DOCUMENT RESUME

ED 334 765 EC 300 511

AUTHOR Freund, Maxine B.
TITLE A Journey with Parents and Infants: Rethinking Parent Professional Interactions. An Early Intervention Training Manual.
INSTITUTION George Washington Univ., Washington, DC. Dept. of Teacher Preparation and Special Education.
SPONS AGENCY Office of Special Education and Rehabilitative Services (ED), Washington, DC.
PUB DATE 90
CONTRACT G008630521
NOTE 118p.; For the final report, see EC 300 510.
PUB TYPE Guides - Non-Classroom Use (055) -- Reports - Descriptive (141)

EDRS PRICE MF01/PC05 Plus Postage.
DESCRIPTORS *At Risk Persons; Check Lists; *Child Development; *Early Intervention; *Evaluation Methods; Home Programs; *Infants; Inservice Education; Naturalistic Observation; Needs Assessment; Neonates; *Parent Attitudes; Parent Education

ABSTRACT

This manual describes the results of a 3-year research project at George Washington University (District of Columbia) called the Assessment as Intervention Project, which explored approaches to parent-sensitive developmental follow-up for prematurely born infants who received neonatal intensive care and their families (N=25). After an introduction, individual chapters address the project's purpose, the shape and focus of the inquiry, insights resulting from parent interviews, implications for practice, and suggestions for professional development. Noted is the project's emphasis on the needs and perceptions of parents in assessment/intervention contacts at 3-month intervals. Appendixes include: a description of the parent-sensitive model used for developmental evaluations; the pre-assessment interview guide; the planning form for assessment/intervention; a checklist for assessment/intervention; a checklist for pre-assessment planning; the assessment report format for the Brazelton Neonatal Behavioral Assessment Scale; the information provided to parents in obtaining their consent for investigational study; post-assessment interview guidelines; procedures for parent interviews at the 9- and 12-month assessments; and final interview questions. Includes 50 references. (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED334765

A journey with parents and infants: rethinking parent professional interactions

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

EC 300511

BEST COPY AVAILABLE

A Journey with Parents and Infants: Rethinking Parent Professional Interactions

An Early Intervention Training Manual

This project is funded by the U.S. Department of Education, Office of Special Education and Rehabilitation Services, Grant Number: G008630521

Project Director: Dr. Janice Hanson, Ph.D.

Principal Investigator: Dr. Maxine Freund, Ed.D.

Project Researchers:

Jane Stanga, M.A., Rosalie Fedoruk, Ph.D. and E. Rebecca White, M.S.

A JOURNEY WITH PARENTS AND INFANTS: RETHINKING PARENT PROFESSIONAL INTERACTIONS

TABLE OF CONTENTS

ACKNOWLEDGMENTS		iii
PREFACE		iv
INTRODUCTION:	ONE RESEARCHER'S JOURNEY WITH THE ASSESSMENT-INTERVENTION MODEL	v
CHAPTER 1:	WHY DO (OR READ ABOUT) A PROJECT LIKE THIS?	1
CHAPTER 2:	THE SHAPE AND FOCUS OF THE INQUIRY	7
CHAPTER 3:	INSIGHT AND UNDERSTANDING FROM PARENT INTERVIEWS	23
CHAPTER 4:	IMPLICATIONS FOR PRACTICE	57
CHAPTER 5:	SUGGESTIONS FOR PROFESSIONAL DEVELOPMENT	66
REFERENCES		72
APPENDICES:	ASSESSMENT RESOURCES	76

LIST OF APPENDICES

APPENDIX A:	A Parent-Sensitive Model for Developmental Evaluations
APPENDIX B:	Pre-Assessment Interview Guide
APPENDIX C:	Planning Guide for Assessment-Intervention
APPENDIX D:	Checklist for Assessment-Intervention
APPENDIX E:	Pre-Assessment Planning
APPENDIX F:	Assessment Report Formats
APPENDIX G:	Consent for Investigational Study
APPENDIX H:	Post-Assessment Interview Guidelines
APPENDIX I:	Procedures for Administering Parent Interviews for 9- and 12-month Assessments
APPENDIX J:	Research Process for Bayley Assessment-Intervention Sessions
APPENDIX K:	Final Interview Questions

ACKNOWLEDGMENTS

We extend appreciation first of all to Mary Ann Fletcher, M.D., Maureen C. Edwards, M.D., Ayman El-Mohandes, M.D., Julie Widman, R.N., and Mary Reed of the Division of Newborn Services of the Department of Neonatalogy at The George Washington University Hospital, for the patient and extensive support during the data collection phase of this project.

We extend thanks to the research assistants, who faithfully typed, transcribed, filed, and organized the never-ending piles of data, correspondence and interview tapes: Kathleen Lipsi, Amy Haupt, and Patricia Blessing.

We extend heartfelt thanks to the families who shared their insights with us, and made this manual possible.

PREFACE

This manual describes the results of a three-year research project funded by the U. S. Department of Education. The project explores approaches to parent-sensitive developmental follow-up for prematurely-born infants and their families. In these pages, we describe one approach to developmental follow-up, what parents told us about their experiences with this approach, and what this might mean for the search for "best practices" in developmental assessment and early intervention services for infants and their families.

The project implemented an assessment-intervention approach to developmental follow-up. Implementing this assessment-intervention model, then gathering and analyzing reactions from parents, has taken each researcher on a journey toward greater understanding of the needs and experiences of parents during assessments. We have learned to listen with our hearts as well as our minds, to examine our own practices and thoughts, and to remain continually open to new insights.

As you read these pages, we invite you to join the journey we have participated in for three years. Rather than reading for a list of "how-to's" about infant assessment-intervention, we hope you will read for an understanding of what we did, to grasp what this group of parents said, and to think through the implications for your own thought and work. Your thoughts and practices in infant assessment may be very similar to those described here, or quite different. The task before each of us is to discern what we believe about parents and infants, what we do in assessment to carry out these beliefs, and what this all means in relation to developmental assessment that meets the needs of parents and infants.

INTRODUCTION

One Researcher's Journey with the Assessment-Intervention Model

When I was asked to join the staff of the Assessment as Intervention project in the fall of 1986, I was excited at the prospect of working on a project to improve understanding of parents of children with special needs. I reacted positively to the general assumptions embodied in the proposal including, 1) that parents care about their children, 2) that parents are interested in detailed information about their children, and 3) that professionals can structure assessment sessions to provide more meaningful information to parents while assessing their children. I was excited about the opportunity to utilize a set of principles I believed to be true about families of children with special needs, as well as having an outlet to share what I had learned from years of experience in working with families.

What I actually gained from my participation in the project was new insight into my own interactions with families of children with special needs. My experience was similar to looking at an optical illusion and seeing the picture change to something new. Several months of working exclusively to understand and meet the needs of a group of parents with babies who had recently left the neonatal intensive care unit gave me a fresh perspective on how much more I had to learn. By looking intently at what I thought I knew so well, I began to realize how much more I had to learn. Further, I began to realize how often as a professional I am presented with new information about working with families, yet how often I have failed to grasp the significance of the information.

One difficulty in describing this process of personal and professional growth is that I am viewing the process retrospectively. Certainly, I always believed in the rights of families to receive meaningful information about their child. However, I unconsciously considered this more true for some families than others. Certain families had seemed eager to absorb any information I could give, while others seemed difficult or uncaring. For instance, some parents seemed to resent my presence and did not appear to want my help. An early entry in a journal I kept during this project questioned whether some families would view us only as an intrusion. I worried that for some families my message about parent involvement would be lost in our differences. However, this notion was disproved as I consistently worked through the assessment format required by the project, which gave me concrete applications of positive assumptions about all parents. I found that persistence paid off with many families. In some cases it took months of phone calls, home visits, and gentle probing to get a parent to accept that I really was interested in his or her opinions and feelings.

In addition to fresh insights about working with families, the assessment format gave me a new perspective on my own skills as I grew professionally during the project. We used a checklist to self-monitor professional behaviors that exemplified the principles of the project. Before participating in the project, I had assumed that I usually

administered assessments in the manner prescribed by the checklist. However, when I completed the checklist immediately after some early assessments, I learned that my image of my behavior as a professional did not always match my actual behavior. As I used the checklist to improve my skills, my relationship with many of the parents improved.

The following case study illustrates some of the ways that my perspectives changed as a result of my experience with this project.

Mary was a single mother who lived with her mother. In her son's hospital chart, the nursing staff had commented that she visited the neonatal intensive care unit infrequently and appeared to lack interest in her child. Mary was one hour late for our first meeting at the hospital. She looked thin, far too thin to be a new mother, and asked few questions. The first home visit did not go particularly well. Again, Mary asked few questions and did not seem particularly interested in the information and suggestions I gave her. My experience to this point confirmed what I had learned about Mary from her hospital chart and our early contacts. I began to assume that this mother really did not care about the help I had to offer. However, at that point, I was required by the format outlined in the project to put in writing what I would focus on in the next assessment. I sat down and thought about Mary as a person and finally made this note: "Throughout the next assessment it will be extremely important to respond to Mary's comments and to give open and honest information. During the assessment I felt that she wanted to be in control of the situation and had a lot of good observations." For the first time it occurred to me that Mary seemed to be a fairly intelligent individual and that in spite of my good intentions I had not given her a chance to be in control of her baby. I began to focus on Mary as an individual with specific needs, and by the end of the project I viewed Mary as an interested and involved parent. I realized then that without thinking through a positive process about this mother, my early perspective of her was shaped by what I had come to know of her from her son's hospital chart.

A professional working with families of special needs infants has endless decisions and judgments to make that affect all future interactions with a particular family. Each of us has different unconscious assumptions that affect our interactions in ways we do not fully realize. Exercises in self awareness may help identify the part we play in a relationship that needs improvement.

Reading through this research and the implications that flow from it may offer an opportunity to bring some of these assumptions to the surface. On the other hand, everything in these pages may fit with your thoughts about parents--but working through the application may still lead to insights about new ways to put them into practice. I invite you to enter this process, to challenge yourself to read with an open mind, and to examine where you are in your journey toward understanding families.

Jane Stanga
September, 1989

Chapter 1

WHY DO (OR READ ABOUT) A PROJECT LIKE THIS?

Research and experience in the field of early intervention have highlighted the risk of developmental difficulties for premature, very low birth weight, and sick infants. Research concerning developmental outcome for these babies indicates risks of subtle long-term developmental problems for these babies even when overall developmental or IQ scores fall within normal ranges. At the same time, it is currently impossible to predict at or near birth which of these infants will experience long-term developmental difficulties. This suggests a need for effective models for periodic developmental intervention for these infants--intervention of less intensity than that provided by most traditional early intervention programs but intervention that offers more than merely collecting developmental data to monitor for major developmental difficulties.

The project described in these pages offers a model for responding to the developmental needs of these infants, with particular attention to the needs and perspectives of their parents. We began with a model of assessment-intervention in which we attempted to facilitate parents' abilities to meet their infants' developmental needs, and in which we continually tried to remain sensitive to parents' needs and experiences during assessment-intervention. During the course of the project, we gathered information to refine this model of assessment-intervention by implementing a plan of service and then following a carefully structured research plan to gather information from parents about how to best meet the needs of their infants and families. This manual tells the story of the implementation of this model, its modification to meet the structure of the research project, and parents' reactions to the features of this model. Throughout the project, the guiding question was, Within the assessment-as-intervention paradigm, what features of developmental assessment-intervention best meet the needs of biologically high-risk infants and their families within the first year of developmental follow-up? We hope that the answers that emerged to this question will assist those in the field of early intervention who are struggling to design appropriate and cost-effective programs for developmental follow-up of high-risk infants.

The specific approach that the project used to address this question arose from several undergirding areas of theory, research, and observation. First, professionals in human service fields have long used a model of the family as a system (Chinn, Winn, & Walters, 1978; Foster & Berger, 1979; Satir, 1967; Stone, 1979; Tiffany, Cohen, Robinson, & Ogburn, 1975). Basically, the family system model suggests that an event that affects any one family member affects the operation of the family as a whole, and therefore it affects each member of the family in some way. Following this paradigm, when a child is born prematurely or experiences serious illness in the newborn period, the experiences surrounding the birth of this infant affect each member of the family. The reactions of the family members to the high-risk birth in turn affect each member's interactions with the infant. Similarly, any

professional intervention on behalf of the baby is an impact on the family system, and as such affects each family member in some way, as well as the family's interactions with the baby. For example, Moran (1985) has reported a study that shows several specific effects of early intervention programs on the parents of the enrolled children. Various early intervention program models affected parents' attitudes and reactions toward their children, their use of social networks, their perceptions of the stress involved in parenting children with handicaps, and their awareness of their own strengths in meeting the needs of their children. Even a brief parent-professional interaction holds the potential to alter, in small ways, a parent's thoughts, feelings or knowledge base in a manner that will affect his/her subsequent interactions with the infant. Professionals in the field of early intervention have increasingly recognized their potential effects on parents and the family system, to the point where we have realized that effective early intervention must take account of the complex nature of family, and their effects on children (Barber, Turnbull, Behr, & Kerns, 1988; Heinicke, Beckwith & Thompson, 1988; Shonkoff, Hauser-Cram, Krauss & Upshur, 1988). P. L. 99-457, with its strong emphasis on sensitivity to family needs and issues, certainly highlights and reinforces this awareness.

Second, psychologists, educators, and others who work with young children have become increasingly aware of the important part that parents play in the unfolding of a child's development. Researchers have linked social-emotional development (Bowlby, 1969; Mahler, Pine, & Bergman, 1975), language development (Seibert & Hogan, 1982), cognitive development (Klein & Feuerstein, 1985), and even physical development (Chatoor, Schaefer, Dickson, & Egan, 1985) to social-interactive exchanges between parents and infants and to the developing relationship between a child and parent.

Third, in addition to providing a crucial component of child development in general, parents provide an important component of early intervention programs designed to enhance the development of handicapped or at-risk infants and children. After decades of debate about nature and nurture, it seems clear that environment, of which parents form a critical part, interacts strongly with biological factors to determine developmental outcome (Meisels & Anastasiow, 1982). In addition, there is a strong rationale for parent participation in planning developmental intervention, particularly with infants. This rationale encompasses at least the following points:

- parents have valuable developmental and temperamental information about their infants that professional evaluators do not;
- parents have an ethical right to participate in decisions about their children;
- parents are in a unique position to advocate for their children and should receive support for that role;
- parents are effective teachers of their children;
- parent participation in developmental teaching

facilitates performance of skills in a wide variety of environments; and

- parent participation opens the possibility of meeting needs of more family members than the infant alone (Bailey & Simeonsson, 1984).

The role of parents as primary decision-makers in matters involving their children's programs and related family issues is emphasized particularly in P. L. 99-457 with its provisions for the Individual Family Service Plan. Early intervention professionals have been called upon to develop skills that will further effective collaboration between parents and professionals. The Individual Family Service Plan focusses particular emphasis on the need to respect parents' perspectives and their right to make decisions for their families. Some early intervention planners have suggested that when family and staff members perceive service needs differently, the service goals should reflect the priorities of the family rather than those of the program staff (McGonigel & Garland, 1988).

Finally, despite a growing awareness of the importance of parents' views of and contributions to the development of their children, professionals still tend to view children's needs from a different vantage point than the parents. Parmelee and Cohen (1985) have described how this difference in vantage point can become an issue in the planning and conduct of developmental follow-up for biologically at-risk infants. When viewing a child's situation from a professional perspective, medical personnel and educators are often unaware of the parents' views on the same situation. Parents, in turn, often do not understand the factors a professional sees when viewing their child, and professionals seem insensitive to needs that seem obvious to parents. Differences in perception, roles, and experience between parents and professionals create a potential for great communication difficulties (Neyhus & Neyhus, 1979). Parents and professionals may differ on issues concerning a child's abilities and deficits (Sexton, Hall, & Thomas, 1984; Sexton, Miller, & Murdock, 1984), the priorities for developmental intervention, and the language that parents and professionals tend to use when discussing a child's needs and behaviors (Vincent, 1985). This difference in vantage point between professionals and parents is accentuated by the current state of inadequate understanding of the complex nature of family systems and of the variables within families that have the most relevance for developmental intervention (Bailey & Simeonsson, 1984). In addition to the differences inherent in the varied positions of parents and professionals in relation to the child, differences in vantage point might also be affected by factors such as parents' previous experiences with disability and difference, which may affect their perceptions of premature birth or special developmental needs (Klaus & Kennell, 1981). Parents' perspectives and reactions to their children and to services are further affected by their own multicultural experiences (Allen, Conners, Neysmith, Roy, Jacob, & Weber 1988), which also may differ from the experiences of the professionals they encounter.

These four points imply that any effective program of developmental intervention must a) recognize the effect of the

high-risk situation and of each intervention on parents and other family members, along with the effects on the high-risk infant, b) effectively involve parents in the intervention process, and c) specifically seek to understand parents' needs and perspectives in relation to their child, while assuming that the professionals involved must learn from the parent both the parents' perspectives and many factors relevant to the developmental needs of this individual child.

In addition to these basic points about families and developmental intervention, several points arise for biologically at-risk infants in particular. First, currently we have no reliable way to predict long term developmental outcome for premature or seriously ill infants. Many very premature, very low birthweight and even very sick infants do very well after several years, especially as measured by scores on global developmental measures (Parmelee & Cohen, 1985; Kitchen, Ford, Richards, Lessender & Ryan, 1987; Brothwood, Wolke, Gamsee, & Cooper, 1988; Klein, Hack, Gallagher, & Fanaroff, 1985). The difficulty with prediction has been compounded by researchers' tendencies to study premature infants as a group, rather than to study premature infants as subgroups divided on the basis of birthweight or specific neonatal events, as well as by attempts to predict outcome from isolated variables rather than a complex of characteristics (Brothwood, Wolke, Gamsee, & Cooper, 1988; Browne, 1989; Fox & Lewis, 1982). Recent research, however, has begun to identify subgroups of premature infants that are at higher risk of developmental difficulties (Gerhardt, Hehre, Feller, Reifenberg, & Bancaiari, 1987; Mansell, Driscoll, & James, 1987; Meisels, Plunkett, Pasick, Stiefel, & Roloff, 1985). For example, Meisels et al. determined that premature infants that experienced severe and chronic respiratory distress were at significantly higher risk of cognitive and motor delays in the second year of life when compared to healthier preterms. Similarly, Hunt (1981) found in her longitudinal study of 114 very low birthweight infants with hyaline membrane disease the onset of downward shifts in IQ from ages 3 through 8 that were neither predicted during follow-up in the first year of life nor were a function of their home environment. Other researchers have found that, even when overall measures such as the Bayley Scales or the Stanford-Binet indicate normal development, many high-risk children show subtle difficulties during the preschool years (Bagnoto & Mayes, 1986; Stanley & English, 1986). Klein, Hack, Gallagher, and Fanaroff (1985) found that the very low birthweight infants they studied performed significantly less well than a control group on visual perceptual and perceptual-motor tasks, even though both groups received comparable IQ scores. Similarly, Hubatch, Johnson, Kistler, Burns, and Moneka (1985) found significant qualitative differences in both receptive and expressive language when they compared children with a history of prematurity and severe respiratory distress syndrome with a control group of full-term children at the same overall expressive language level. Field, Dempsey and Shuman (1982) found, in later childhood, significant language delays accompanied with behavioral problems, including hyperactivity, in their cohort of preterm infants with respiratory distress syndrome and with post term infants with fetal hypoxia. Thus, two points seem clear: first, we are not yet in a position to predict at or near birth which individual children in a high-risk group will experience long-

term developmental difficulties, and second, many of the children who will show more subtle learning difficulties later will not show obvious signs of overall delay, and thus would probably not be identified and served by most existing early intervention programs.

In fact, the group of high-risk infants that will develop subtle developmental differences may not need service of the intensity provided by most existing early intervention programs. However, they may benefit from less frequent developmental interventions. The following points provide a rationale for such an approach.

First, parents' anxiety about the child's well-being and development is high at the time of a premature or other high-risk birth, and remains high for some time afterwards. There is evidence that this anxiety, or some other aspect of experiencing a premature birth, alters parents' interactions with the baby (Fox & Feiring, 1985). At the same time, evidence suggests that quality parent-child interactions improve developmental outcome for high-risk babies (Siegel, 1985). Thus, periodic information from a developmental specialist to facilitate optimal interactions would facilitate the infant's development. There is also preliminary evidence that developmental intervention can effect at least short-term gains for two groups of babies noted to be at especially high risk for developmental difficulties--very low birthweight babies and those that experienced severe respiratory distress syndrome (Furuno, O'Reilly, & Ahern, 1985). Bustan and Sagi (1984) also found that intervention that offered information to mothers about the characteristics and needs of premature infants while the infants were in the hospital positively affected interactions between the mothers and babies 3 months after discharge.

These findings indicate a need for periodic developmental follow-up, with some level of developmental intervention, for high-risk infants after they leave the neonatal intensive care unit. The need seems most acute for babies who do not evidence obvious handicaps and therefore would not receive service from most available early intervention programs, although more severely involved babies would also benefit from follow-up that would lead to referrals to appropriate community agencies. This points to a need for effective, efficient models for service to these infants.

The model that was implemented and refined in the Assessment as Intervention research project, which is described in this manual, offers a viable approach to this kind of developmental monitoring combined with intervention for babies at-risk of developmental difficulties due to premature birth with its accompanying complications. The approach pays particular attention to the needs and perceptions of parents as they relate to the services offered to their babies, and incorporates detailed information from parents about how to best convey developmental information tailored to their needs and the needs of their children. The model as utilized in our research design is based on contacts at three month intervals with the infants and parents. Each contact with a family involves providing a great deal of developmental information and many suggestions to parents in addition to monitoring the child's developmental progress.

Because of the flexibility and detail of the model, it allows for individualization to family needs.

Although this project addresses the specific needs of infants who are biologically at-risk because of perinatal and neonatal events, the premises and flexibility of the model suggest that it may be adaptable for use with other high-risk populations as well. This includes groups of infants with metabolic disorders that require developmental monitoring (e.g., PKU), and infants in high-risk environments (e.g., infants of adolescent parents). In addition, the principles of interaction between parents and professionals, which the parents in the project described in detail, readily apply to interactions with parents of infants with any special need.

Chapter 2

THE SHAPE AND FOCUS OF THE INQUIRY

Introductory comments

This chapter describes in detail both the clinical process and the research design of the project. Hopefully, readers will look at these descriptions less as a "research report" than as an opportunity to build an in-depth understanding of how the inquiry proceeded. As you read, we urge you to consider your own assumptions about parents, beliefs about developmental assessment, and practices in infant assessment situations, identifying the points where you wholeheartedly agree with the course of this project, where you disagree, and where you might be challenged by a new thought or perspective.

This chapter forms a critical foundation for understanding the results of the research and the practical implications of the parents' responses to our questions, since the parents' comments and descriptions were clearly shaped by their assessment-intervention experiences throughout the project. Therefore, the results and implications must be understood and evaluated in the context of the assessments and parent-professional interactions that these parents experienced. An understanding of their experience is necessary in order to check out whether our understandings of parents' reactions and preferences would hold in another infant assessment setting.

This inquiry addressed the question: Within the assessment-as-intervention paradigm, what features of developmental assessment-intervention best meet the needs of biologically high-risk infants and their families within the first year of developmental follow-up?

The issues discussed in chapter one led to certain implications for the research approach and methodology. These implications concerned which group of infants and parents to include in the study, in what context to conduct the study, and what type of research design to use. Hence, this chapter discusses the infants whose parents were the respondents in the study, the assessment-intervention model that formed the context of the study, and the naturalistic approach to research that provided the structure for the inquiry.

The Infants in this Study

One group of babies in need of developmental intervention comprises biologically at-risk babies. For the purpose of this study, these infants were defined as infants who were cared for in the neonatal intensive care unit and who experienced one or more of the following:

a) born at less than 34 weeks gestation
b) birthweight less than 1500 grams
c) perinatal asphyxia (5 minute Apgar score less than 5)
d) neonatal seizures
e) a diagnosis of bronchopulmonary dysplasia (BPD) or chronic lung disease prior to discharge
f) a diagnosis of overwhelming sepsis (bacterial or viral)
g) abnormal neurological findings or abnormal tone on routine examination in the nursery
h) intraventricular hemorrhage (IVH) or periventricular leukomalacia (PVL)

Since the purpose of this study was not to predict developmental outcome on the basis of perinatal events, but rather to design a model of developmental monitoring and intervention, we included all of the infants served in one neonatal intensive care unit during the time of the study, if they fell within these parameters and their parents agreed to participate. Once the project began, the project staff enrolled consecutive infants and their parents who met these criteria, until 30 families were participating. Two families that we approached in the hospital declined to participate. Twenty-five of the 30 families who enrolled completed the entire project. Of the five families who did not complete the project, one completed all but the final interview, which they did not schedule due to a complicated situation in their family at the time; one agreed to participate while in the hospital, but did not keep any of the appointments afterward; two moved and did not leave information about a forwarding address or phone number; and one moved out of the area.

Table 1 provides an overview of some characteristics of the 24 infants and families who completed the study.

Table 1

Demographic Characteristics of Study Infants and Families

Infant's Pseudonym	Infant's Sex	Gestational Age	Birthweight	Mother's Marital Status
Zachary	M	25 wks.	820 gm.	single
Brendan	M	25 wks.	820 gm.	married
Jimmy	M	26 wks.	570 gm.	married
Debbie	F	26 wks.	650 gm.	married
Leslie	F	26 wks.	820 gm.	married
Jerry	M	27 wks.	780 gm.	single
Marc	M	28 wks.	1240 gm.	married
Tabitha	F	29 wks.	990 gm.	single
Patty	F	29 wks.	1040 gm.	married
Greta	F	29 wks.	1260 gm.	married
Anita	F	29 wks.	1520 gm.	married
Triplets				single
Brent	M	30 wks.	1400 gm.	
Mitch	M	30 wks.	1120 gm.	
Chris	M	30 wks.	? gm.	
Twins				single
Ned	M	30 wks.	1280 gm.	
Nancy	F	30 wks.	1300 gm.	
A.J.	M	30 wks.	1550 gm.	married
Bobby	M	31 wks.	1700 gm.	single
Timothy	M	31 wks.	1060 gm.	single
Billy	M	31 wks.	1320 gm.	single
Donnie	M	31 wks.	1760 gm.	married
Brenda	F	31 wks.	2060 gm.	married
Tonya	F	32 wks.	1500 gm.	single
Ellen	F	32 wks.	1540 gm.	married
Callie	F	32-33 wks.	1900 gm.	married
Twins				married
Jackie	F	33 wks.	1780 gm.	
Karen	F	33 wks.	2470 gm.	
Katie	F	33 wks.	1990 gm.	single
Kevin	M	33 wks.	2440 gm.	married

Notes

1.Marital status given as of the time of the infant's birth. In several families, marital status changed during the project.

2.Families were sequentially enrolled in the project, as the infant neared discharge from the neonatal intensive care unit.

3.Maternal age varied from approximately 19-38 years at time of infant's birth.

4.Parent's educational backgrounds varied widely.

5.Families' economic status varied widely.

6.Racial/ethnic backgrounds included 1 Asian, 1 Hispanic, 14 Black, and 9 white families.

The Assessment-Intervention Model

On the basis of previous research, experience, and observations, we saw a need for the identified infants and their parents to receive periodic developmental intervention that included more than strictly assessment of developmental status, but not necessarily the daily or weekly services provided by available early intervention programs. To meet this need, we selected a model that utilized the concept of assessment-as-intervention. This concept, consistent with the image of a family operating as a system, recognizes that a developmental assessment of an infant inherently functions as an intervention in a family system. In order to optimize a developmental assessment as a positive intervention, and in particular to structure an assessment as a developmental intervention for the infant and parents, we must carefully think through the best ways to approach an assessment in order to produce a helpful developmental experience and learning session for parents.

Several authors had previously discussed the concept that an infant assessment can also provide a helpful developmental intervention if the evaluator communicates effectively with the child's parents and involves them appropriately in the assessment process (Bradley-Johnson, 1982; Brazelton, 1981). These authors and several others have discussed ways to modify an infant's assessment in order to better meet the needs of parents and to use the assessment time to share important developmental information with parents (Brown, 1975; Hanson, 1984; Rogers, 1978). Some of the advantages of using developmental assessments in this way include efficient use of time and resources and the potential of developing sensitivity to parents' as well as infants' needs during the testing process. An assessment-intervention utilizes developmental assessments as an opportunity to explain infants' responses to parents, answer parents' questions about development, support parents in their role and suggest activities to facilitate optimal infant development. This approach is particularly useful for meeting the developmental needs of high-risk infants, since contacts with the family may be spaced by several months. Designing assessment experiences to meet parents' needs for developmental information and intervention while simultaneously gathering systematic and periodic information about the infants' developmental status allows developmental evaluators to collect the data necessary to monitor the infants' developmental needs and to make appropriate suggestions to parents for interacting with the infant, within the context of one visit with the baby.

At the start of the project, we had a detailed model for developmental assessment with infants and young children that was consistent with the concepts of assessment-as-intervention (Hanson, 1984). This model included principles for interactions with parents concerning a developmental evaluation and detailed checklists of points to consider when designing a child's evaluation to meet parents' needs (see Appendix A). This parent-sensitive model for developmental assessments was based on previous research (Hanson, 1984). The earlier study included questionnaires completed by parents before their children's assessments, observations of the assessments, and two sets of open-ended interviews with parents after the assessments, within an ethnographic research

framework. Thus, the model was grounded in parents' and children's actual experiences with developmental assessments, and in specific needs and reactions that parents had expressed. The model formed the starting point for the research described here. Throughout the assessment-intervention process, the original model was modified to better meet the needs of the parents in this project. The research process also provided detailed explanations from parents about what makes this assessment-intervention process work.

Early Modifications to the Assessment-Intervention Model

Early in the project, it became apparent that, while the original checklists contained a wealth of useful items to guide interactions with parents, they did not offer a readily-useable format. Therefore, we modified the arrangement of the items, and placed them in two checklists: a Pre-Assessment Interview Guide (Appendix B) and a Planning Form for Assessment-Intervention (Appendix C). We recognized the need for a concise checklist to use during the actual assessment sessions, to help an assessor remember the essential components of assessment-intervention at the times they should occur. In response, we developed a short Checklist for Assessment-Intervention, for use during each developmental assessment (Appendix D). To complete the model in a concise format, there is a shortened list of essentials for pre-assessment planning (Appendix E).

These checklists represent an attempt to specify concrete applications of the principles of assessment-intervention. These principles, which also emerged during the earlier research study (Hanson, 1984), include the following:

1. Find out what understandings, expectations and needs a family brings to an assessment. These set the context for parents' reactions. (This is one of the tasks of the pre-assessment interview.)

2. Aim to establish a caring, comfortable relationship between professional and parents, with contacts before, during and after assessments. Convey that we care about both babies and their parents.

3. Provide a great deal of information for parents, preferably in the form of ongoing dialogue before, during and after testing. This information should cover at least the following: the purposes of developmental evaluation, what will happen during an evaluation, what their roles as parents include during an evaluation, the meaning of the test, the implications of the child's performance, and approaches to the child's developmental needs.

4. Involve parents as partners and peers in the process of planning and implementing a developmental assessment. Set clear but flexible guidelines. Respect and listen to parents' knowledge of their own children.

5. Strive to increase the validity of test results by gathering and incorporating information from parents, including information regarding their observations of their child at home, a comparison between the child's test performance and the child's behavior at home, their needs and concerns about their child, and ways to arrange the test situation to encourage the child's best performance.

Some of the points reflected in these principles, which may appear on the original checklists in Appendix A, have disappeared from the shortened versions. This is not necessarily because the items are not important, but because some of the items are inherent in the structure used in this project, and thus did not require specific planning. For example, the model recommends placing an assessment in the context of a continuing relationship between parents and a professional. Since the same researcher worked with the same family throughout the project, and each assessment included contacts before and after the actual assessment with the pre-assessment and post-assessment interviews, this aspect of the model happened automatically.

Is is important to note that, when sharing information with parents, the aim is to convey broad principles and understandings along with specific items of information, so that parents will be equipped to apply principles of development and understandings about assessment to other situations with their children. While an item may be a brief note on the checklist, it should remind the developmental specialist to discuss related ideas in detail with parents.

Assumptions about Parents

We found it helpful to delineate the assumptions that seemed to underlie our interactions with parents. The basic assumption is that professionals should approach parents as peers, partners, joint planners and joint decision-makers in the developmental assessment process. This follows from two assumptions:

1. Both parents and professionals can make valuable contributions to the assessment-intervention process. Acting in accordance with this assumption involves recognizing several points, including:

   a. Professionals should be consultants to parents.

   b. Parents are the experts on their own children. Although not all parents initially realize the importance of their observations and knowledge of their children, parents make observations while caring for their children, and those observations provide an important contribution to a good developmental assessment.

   c. Parents' knowledge of their children should be incorporated into the planning of an assessment session.

d. Test results and developmental information from parents deserve equal weight.

e. Parents have "final say" about whether an assessment represents their child's abilities.

2. The professional's role is to facilitate parents' decision-making, not to get parents to comply with recommendations. Acting in accordance with this assumption means at least the following:

a. Parents need enough information to evaluate the validity of test results.

b. Parents need enough information about their child's development and needs to make decisions about pursuing recommendations.

c. Parents should be offered the opportunity to participate in decision-making from the first encounters.

d. Professionals must aim to establish an environment where parents feel free to share opinions and observations.

e. Professionals should take the lead from parents, rather than following pre-conceived ideas of how to meet families' needs.

Staff Preparation to Apply the Principles of Assessment-Intervention

In preparing to apply this model of assessment-intervention, the researchers first immersed themselves in conversations about the principles of assessment-intervention, what they meant, how we would apply them, and how to use the checklists during an assessment. We talked about the Bayley Scales of Infant Development (Bayley, 1969), what a parent would need to know in order to understand our use of them, and how we would phrase explanations. We went through the Bayley Scales item by item, talking about all the components of development that a developmental specialist observes and thinks about when presenting these items to a baby, and how we could explain these observations in detail, so that a parent could learn to make similar observations about development while we were administering assessments. Then we practiced assessments, observing one another and marking off the items on the assessment-intervention checklists, and discussing afterwards how the activities of the assessor did or did not fit the principles of assessment-intervention. We also developed assessment report formats (Appendix F) that included explanations of information parents would need in order to understand the developmental statements in reports concerning their babies.

Although we generally talked in terms of principles and descriptions, we did want to ascertain whether it was possible to apply the assessment-intervention model in a relatively consistent, even though flexible, way. Thus, after discussing and practicing, the project director observed each of the

other researchers at least once during an assessment-intervention, marking off the items on the Checklist for Assessment-Intervention as the researcher covered them in her interactions with the infant and parent. The number of items covered by the researchers in relation to this checklist ranged from 83% to 94%, with an average of 90%. In addition, the project director's checkmarks on the checklist matched the researcher's own notations on the checklist at rates ranging from 89% to 100%, with an average of 97%. Thus, it appeared that, as a team of clinicians and researchers, we were able to reach a common understanding of how to apply the principles of assessment-intervention, and then to apply these principles consistently in our interactions with parents.

At first glance, the use of checklists may seem at odds with the ethnographic approach of the research. Upon careful consideration, however, they are quite consistent, for at least two reasons. First, the items on the checklists grew out of previous field observations and interviews with parents. Second, the items are descriptions of things that happen during assessment-intervention interactions between a parent and a professional. As such, they are in no way an attempt to quantify the aspects of these interactions, and we never used them as a quantitative research observation tool. Rather, the checklists served as descriptive reminders of ways to implement the principles of assessment-intervention, and as such, they worked very effectively.

Ethnography and Naturalistic Inquiry

Several factors argued for a flexible, open-ended, in-depth research design to approach the problem of developing a model to best meet the developmental intervention needs of high-risk infants and their families. First, there are relatively small numbers of appropriate infants available to study in any program within a reasonable amount of time. This argued for an in-depth look at the available families. Second, the complex nature of family systems and of the interactions that take place between infant, parents, and assessor would render traditional research designs with a few pre-determined variables ineffective. A number of researchers in education and other social fields have expressed concern about whether the more traditional research designs can capture the kind of meaningful information needed to apply research results in the context of complex relationships between people. (Barritt, Beekman, Bleeker, & Mulderij, 1979; Blumer, 1969; Eisner, 1983; Stainbeck & Stainbeck, 1984, 1988). Third, the individual needs of various families required a research plan that would take account of these needs and result in a flexible model, with provisions to adapt to parents and professionals that serve high-risk infants. The complex and individual nature of family needs also argued for a design that afforded parents the position of expert about their needs and about the needs and responses of their infants in a family context, allowing them to teach us what factors an effective model for developmental intervention should reflect.

Thus, this research aimed to understand parents' perceptions, experiences, and needs as they moved through the developmental assessment-intervention process. With this

thought in mind, several concepts underlying ethnographic research proved particularly helpful when designing and thinking about the project. First, in an ethnographic study, the researcher enters another culture and seeks an understanding of that culture. In this study, the parents of infants born prematurely, cared for in a neonatal intensive care unit, and followed by a developmental specialist formed a "culture" somewhat different than that of the researchers, because of their experiences as the parents of these infants. The researchers attempted to enter that culture and build an understanding of the feelings, needs and interpretations of those parents. Second, an ethnographic researcher describes what s/he sees and hears in that culture, as observed in a natural setting. We found it valuable to observe and interview in the natural settings of these parents, with their babies in the hospital and in their homes or a clinic at the time of a developmental assessment-intervention. In this way, the researchers were as close as possible to the situations experienced by the parents. In addition, placing the study in a natural context, with all of the complexities and actualities of a clinical setting, furthered the possibilities that our understandings would be closer to actual experience, and that the suggestions that would flow from the study would translate into clinical practice afterward. Third, the primary methods of ethnographic research include participant observation and interviewing. Again, these methods offer excellent tools for building understandings about the experiences and interpretations of a particular set of people. They allow for the respondents to direct the content of the findings much more so than tools that pre-determine all of the important variables for the study. Fourth, questions and understandings emerge during the process of an ethnographic study. This allows for the researchers to learn as they go, and to modify a flexible study design during the course of the study, in accordance with the understandings that emerge.

Finally, an ethnographic researcher considers the members of the culture under study the experts about that culture, and attempts to understand the meaning of the culture as the people express it (Spradley & McCurdy, 1972). In the research described here, parents were the experts about parenting a biologically high-risk infant and moving through a sequence of developmental services from that perspective. The researchers needed to learn from the parents what assessment-intervention looked like from their side, and from that to discern what would be the most effective style of intervention to aid them in the process of parenting this high-risk child. The importance of emphasizing parents' perspectives and needs was reinforced by the awareness that the precise developmental outcome for these infants was uncertain, and these mothers and fathers were called upon to parent in the context of that uncertainty.

This attitude toward parents arose from the need to seek to understand parents' perspectives. It also coincided with the clear trend toward greater parent participation in early intervention programs, developmental assessment, and educational and medical decision-making. The inquiry approached parents as equal partners with the researchers, and afforded them the position of colleague as we endeavored to shape the style of interactions with parents during the developmental assessment-intervention process.

Although we had not read Lincoln and Guba's (1985) book on naturalistic inquiry when we first designed this study, we have since found their thought very helpful and applicable. The tenets of the naturalistic inquiry paradigm are quite consistent with the assumptions of this inquiry, and quite consistent with the parent, family, and educational perspectives discussed here and in chapter one. Following is an outline of these tenets as presented by Lincoln (1988), with a discussion of how they apply to this inquiry.

(a) The naturalistic inquiry paradigm assumes that there are multiple, socially-constructed realities, created by the people who enact and experience them. Blumer (1969), in his explication of symbolic interactionism, has described one very helpful approach to understanding "multiple, socially-constructed realities." Very briefly, he posits that human beings act toward things on the basis of the meanings that the things have for them; the meaning of such things is derived from, or arises out of, social interactions; and meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he or she encounters. In relation to the inquiry described here, parents create multiple realities, or meanings, related to parenting children with special needs and experiencing assessment-intervention services. These interpretations of experience will affect parents' reactions to interactions with professionals and to the services they receive. At the same time, professionals create meanings on the basis of their own social experiences, and these will affect their reactions to interactions with parents. Professionals' and parents' interpretations of the same experiences may not match. Effective collaboration between parents and professionals requires that professionals build an understanding of the "multiple realities" that parents bring to an assessment-intervention setting, and that the sessions take account of these various interpretations of experience. The multicultural backgrounds of the parents and professionals involved in assessment-intervention may lead to diversity in interpretation of the experience, but even apart from cultural difference, the difference in experience between a professional and a parent in relating to a particular child can create a difference in interpretation and meaning for the professionals and parents involved. Thus, the assumption of multiple, socially-constructed realities in the naturalistic inquiry paradigm fits well with the assessment-intervention situation.

(b) The paradigm considers interactivity between researchers and respondents inherent, unavoidable, and an opportunity for mutual learning. Again, this is consistent with the assumptions and approaches of the assessment-intervention model. Effective assessment-intervention cannot occur without effective interactions between parents and professionals, and these interactions offer an opportunity for mutual learning.

(c) When considering generalization of research findings, the naturalistic inquiry paradigm assumes that there are no time- and context-free laws. We must determine if our understandings hold in another time and place--e.g., if another set of parents experiences the world in accordance with our previous understandings.

(d) The paradigm of naturalistic inquiry considers linear, causal chains insufficient to describe the complexity of situations. In this case, linear, causal chains are insufficient to describe the social situations relevant to parent-infant interactions and parent-professional interactions. The past several decades of research and experience with parents, families and children have heightened our appreciation for the complexity of these interactions, and have highlighted the inadequacy of linear causal models for explaining and describing them. Research that assumes that more complex relationships lie behind family and parent-professional relationships will more likely produce understandings that will transfer to the real world in meaningful ways.

(e) Naturalistic inquiry recognizes that science cannot be value-free. Early intervention is not value-free, and neither are the practitioners and researchers within the field. A research paradigm that openly recognizes the impact of values on choice of research questions, methodology and interpretations allows the researcher to account for these values and their influence on the research process.

Thus, there seems to be a good match between the issues and needs that arise in the context of an infant assessment-intervention, and the assumptions and approaches of ethnographic or naturalistic research. The following section describes our specific applications of these approaches during the inquiry.

The Research Design

With thoughts about ethnography and assessment-intervention as a foundation, we embarked upon a journey with the parents and infants in the study. Our task was to ascertain parents' perceptions of their own needs during a year of developmental follow-up for their infants, from the time the infants went home from the neonatal intensive care unit, through the time of a developmental assessment-intervention at approximately 12 months corrected age, and to figure out what features of developmental assessment-intervention would best meet the needs of these high-risk infants and their families within the first year of developmental follow-up. The project employed a research design that included the following components: (a) an in-hospital observation of parents visiting their infants, (b) administration of the Brazelton Neonatal Behavioral Assessment Scale at 40-42 weeks gestational age, (c) pre-assessment interviews, assessment-interventions, and post-assessment interviews at 3, 6, 9 and 12 months (corrected ages), and (d) evaluative interviews at the end of the series of interventions.

A basic understanding of the framework of the research forms an important foundation for interpreting the parents' responses as participants in the research. In addition to building an understanding of the context of parents' comments as they appear in the next chapter, reading this section may suggest some activities that could be modified and then used in another follow-up program as a tool for gaining an understanding of parents' positions and perspectives.

Whenever possible, one researcher moved through the entire process with a family. Due to a personnel change, several families changed researchers very early in the study, after the hospital observation or the Brazelton assessment, and several others after the assessment-intervention at 3 months corrected age. Reactions to these changes, on the part of both the researchers and the parents, along with the quality of the relationships that developed when researchers and family remained together over a period of time in the study, reinforced the wisdom of maintaining a constant relationship whenever possible. This policy enhanced the opportunity for a researcher to develop a relationship of trust with the parents, and thus increased the parents' openness when sharing reactions to the assessment-intervention process. The opportunity to get to know a family well also enhanced the researchers' ability to ask questions to clarify issues discussed during the interviews. In addition, using the same person to ask the research questions and to perform the assessment-interventions increased the potential applicability of the results of the study to other clinical settings, since the researchers experienced the contingencies of a clinical setting first-hand, and developed understandings from that perspective.

First, the researcher visited with the parent(s), observing the baby in the hospital and watching the parent-infant interactions. This observation, of at least half an hour in length, 1) enabled the researcher to meet the parent, explain the project, and obtain informed consent to participate in the study (see Appendix G), 2) helped the researcher to develop an understanding of some of the parents' needs and feelings at that time, which formed an important foundation for later interactions with the family, and 3) enabled the parents to begin a relationship with the researcher. After the hospital observation, the researchers wrote notes concerning observations that might relate to parents' reactions to later developmental assessments. The observations served as a tool to build understanding of the parent(s)' needs and feelings in relation to their baby at this time, providing an important foundation for understanding and interacting with parents at later visits.

The next visit with the family involved administering the Brazelton Neonatal Behavioral Assessment Scale at 40-42 weeks gestational age. Most of the babies had been discharged from the hospital by that time, so the Brazelton Assessments occurred at home. For the few babies who remained in the hospital at 40-42 weeks, the Brazelton Assessment took place in the hospital at a time when the parents could attend. The interactive opportunities that occur during administration of the Brazelton Scale tend to be somewhat less overwhelming for parents than those of some other assessment tools. We found that the Brazelton Scale provided parents with a nonthreatening but specific experience with assessment and a framework for the next step of the research process: the parent-professional planning of the next developmental assessment. Without such a framework, it would have been difficult for parents, most of whom had not experienced developmental assessment for infants before, to have the knowledge base needed to answer questions about how they would like an assessment-intervention structured. Since the goal of this part of the project was to facilitate an interactive

process between parents and assessors, rather than to gather data for prediction of developmental outcome, the use of the Brazelton Scale is particularly appropriate.

The principles of assessment-intervention formed the basis of the interactions with parents during the Brazelton Assessments. Each Brazelton Assessment took place in the context of a continuing relationship with the parents and baby (i.e., the researcher had met the family in the hospital, and talked with the parents on the phone before the Brazelton Assessment). These contacts provided an opportunity to gain an understanding of the questions, expectations and needs the parents would bring to the first assessment session. The Brazelton Scale, when used as an intervention tool, provides an excellent forum for offering information to parents, when the assessor explains the items and the baby's responses throughout the assessment (see Nugent, 1985 for detailed suggestions about using the Brazelton Scale in this way). Even at this early age, parents have learned a lot about their baby from their own observations. Recognition and validation of these parent observations fit easily into assessment conversations. To further the development of a continuing relationship as the context for an assessment, contacts after the Brazelton Assessment included sending a written report to the family (see Appendix F), with a follow-up phone call to discuss the report. Parents also routinely received the researcher's phone number, so they could call with questions if they felt the need.

The next planned contact with the family was a pre-assessment interview, shortly before 3 months corrected age. The purposes of the pre-assessment interview were to schedule an assessment-intervention near 3 months corrected age, and to obtain input from the parents about how they saw their needs in relation to the assessment. The input was gathered by asking the parents to respond to a checklist of options for the assessment, as well as to answer some more open-ended questions (see Appendix B). In addition, this part of the process enabled the researchers to explain the assessment in advance, to set the tone for parents' involvement in the assessment, and to discuss parents' concerns about their babies in preparation for the assessment. This pre-assessment planning and conversation forms an important component of the assessment-intervention process, with specific opportunities for parents to share in the assessment planning process. The researchers noticed that parents tended to share fewer specific ideas of how they wanted an assessment to proceed at the beginning of the project, and to rely more on the researcher to direct the planning. Presumably, this was because, at the beginning of the project, they had limited experience with assessments, and therefore fewer specific preferences. Perhaps they also had limited experience with parent-professional relationships that afforded them the opportunity to have such an active role in planning interactions. The researchers also noticed, not surprisingly, that parents' need for explanations about what to expect from an assessment decreased as time went on and they had experienced several assessments.

An assessment-intervention then took place at approximately 3 months of age (corrected age). This assessment-intervention was planned to coincide as closely as

possible to the parents' preferences expressed during the pre-assessment interview. In addition, the original model of assessment-intervention supplied guidelines and principles for the assessment-intervention sessions (see Appendices A, C, and D).

Before each assessment-intervention session, the researcher would use either the Planning Form for Assessment-Intervention (Appendix C) or the Checklist for Assessment-Intervention (Appendix D) as a tool for individualizing the assessment-intervention session for a particular family. On the basis of the pre-assessment interview and any other previous contacts with the family, the researcher would go through the checklist and mark with an asterisk the items that she considered particularly important for this assessment-intervention session with this family. Then she would identify the reasons that she highlighted these particular items, and make notes about her reasons. This forced the researcher to think about which aspects of the assessment model seemed to respond most closely with the needs of a particular family, based on the information that the parents had shared. This part of the process also helped the researcher to think about a parent as an individual in relation to the assessment-intervention process.

Using the Bayley Scales of Infant Development as the basic assessment tool, combined with informal observations and conversation with the parents concerning the baby, the researcher then did an assessment-intervention with the parents and infant. During and after the assessment-intervention session, the researcher would check off the items on the Checklist for Assessment-Intervention if she had covered them in the session. This checklist served as a self-monitoring tool (i.e., the researcher could monitor the consistency and completeness with which she followed the assessment-intervention model), and as a reminder of the essential elements of the assessment-intervention model during the actual sessions.

A post-assessment interview followed each assessment-intervention. At the beginning of the project, these interviews were always scheduled on a day following the assessment-intervention. As the project proceeded and the researchers became better acquainted with the parents, they sometimes conducted these interviews immediately following the assessment-intervention session. This allowed for immediate reactions to the assessment-intervention, while the experience was very fresh in their minds, and simplified the scheduling process. This was particularly important as the babies got older and parents became increasingly involved in other family, child, professional and personal activities.

The purpose of the post-assessment interviews was to have parents comment on the assessment-intervention experience. At the 3-month and 6-month post-assessment interviews, the researchers asked open-ended questions, asking the parents to identify what they did and did not like about the assessment-intervention that they had just experienced. (See Appendix H for details about the procedures for the post-assessment interviews and delineation of the questions.) During the interview, the researchers recorded the parents' responses by writing down lists of things the parents did like and things

that they would like changed at subsequent assessments. After making the lists, the researchers would read them back to the parents and ask for clarifications and changes, so that the lists matched what the parents had intended to say.

At the 9-month and 12-month interviews, the researchers felt a need to provide more specific questions to the parents, to check out whether the understandings that they had reached by that point matched what the parents had been saying. Thus, the post-assessment interviews at these ages followed a different format (see Appendix I). Although these interviews offered more specific options for the parents to respond to, the researchers always began with the most open-ended questions, and elicited as much information as possible at this level, before moving on to the more specific questions. The researchers recorded the parents' responses as notes on the papers that listed the questions.

A research project asks more questions and collects more data than would be practical in a purely clinical program. However, a brief post-assessment interview format immediately following assessments would be quite practical for clinical programs. Simply asking parents after an assessment what they liked and what they would like done differently during later assessments would provide the clinician with valuable information, especially once good rapport had been established between the clinician and the parents. Asking these questions would also provide another way to send a clear message that the clinician wanted to structure assessment-interventions to meet parents' needs.

This sequence of pre-assessment interviews, assessment-intervention sessions and post-assessment interviews was repeated with each family at 6, 9, and 12 months (corrected ages). (For a detailed summary of the research process for each assessment-intervention, see Appendix J.) After all of these interviews and assessment-intervention sessions, the researchers met with each family for an open-ended evaluative interview at the end of the project. Guiding questions for this interview were developed by the project staff on the basis of their experiences in the project up to that point (see Appendix K). The questions, however, were only a guide, and parents were asked to share reactions and suggestions in an open-ended fashion. The interviews were taped and transcribed for data analysis. In addition to asking the open-ended questions, the researchers utilized a list of themes that they had identified from all of the previous contacts with the family, and asked the parents to confirm, disconfirm, or clarify these themes. This provided a final opportunity to determine whether the researchers had interpreted the parents' comments up to that point in the ways that the parents intended them, and whether the researchers' understandings provided an accurate reflection of the things that the parents had described throughout the project. This process, like the feedback of information to parents during earlier interviews, served as the project's application of "member checking," as described by Lincoln and Guba (1985).

A brief sketch of the process that the researchers moved through with each family appears in Table 2.

Table 2

* Hospital observation

* Brazelton assessment-intervention
(40-42 weeks corrected ages)

* Bayley assessment-interventions: > repeated at
--pre-assessment interview > 3, 6, 9
--assessment-intervention session > and 12 months
--post-assessment interview > (corrected ages)

* Final evaluative interview

Throughout this project, we made every attempt to make the study and its results clinically relevant, addressing the early intervention issues and research paradigm issues that we discussed earlier. The study responds to the interplay of clinical and research paradigm issues in several ways. First, the study was based in a natural context. The researchers provided developmental follow-up and some intervention services, confronting the contingencies of that situation, as well as interviewing parents and collecting data about the situation. Second, continual interactions between parents and researchers were integral to the project, with a high degree of respect for the value of parents' contributions to both the assessment-intervention process and the research process. Parents and professionals jointly planned each assessment-intervention session; researchers continually modified research questions and insights, adding new facets of exploration as the study proceeded, on the basis of parent input. Parents retained continual input into the interpretation of their comments through the member checking process.

Third, the study allowed for parents to provide insights about the impact of their various backgrounds and experiences through the open-ended interview process, within a consistent relationship between a researcher and each family. Observing each family in the hospital also allowed for some insight about part of that family's experience that may have affected their reactions to developmental follow-up. Each parent was afforded the opportunity to describe his or her own experiences, understandings and reactions in an open-ended, individually responsive setting. Finally, the researchers continually explored the impact of their own values and beliefs through team discussions, individual reflection and journalling. Thus, the resulting recommendations about assessment-intervention are grounded in research data, inherently consistent with educational beliefs about parents and infants, and based on experience in actual clinical settings.

Chapter 3

INSIGHT AND UNDERSTANDING FROM PARENT INTERVIEWS

The process described in chapter two generated a great deal of data in the form of notes about observations and parent interviews, journals about the researchers' experiences with and thoughts about the assessment-intervention process, and tapes of interviews with parents. Of all the data collected, the final evaluative interviews form the main foundation for the information that we share with you in this chapter. These interviews, which 25 families completed, were taped, transcribed, and then analyzed in detail according to the procedures described below.

Although the typed transcriptions of these interviews form the foundation for the detailed analysis presented here, the researchers' relationships with the families and the understandings that they gained about each family during the earlier phases of the project shaped and undergirded the final interviews. Clearly, the experience the researchers shared with the parents during the assessment-intervention sessions created common ground for discussion. In addition, the relationships established during the year of interviews and assessments developed into invaluable rapport between the researchers and many of the parents. This rapport is essential for good open-ended interviews. Concretely, the researchers' delineation of the themes that they had identified from earlier contacts with the families formed the basis of member checking at the final interviews. The understandings that the researchers gained from the earlier interviews also helped to shape the questions for the final interviews--both the guiding questions for the interviews, and the probing questions that the researchers asked in order to gain a deeper understanding of the parents' responses during the actual interview sessions.

The Process of Analysis with the Final Interviews

The procedures for analyzing the transcripts of the final interviews grew out of guidelines from three sources. First, Barritt, Beekman, Bleeker and Mulderij (1979) describe a process of looking for forms (significant points) and common forms (themes) in written qualitative data. Second, the earlier study (Hanson, 1984) that provides the original model of assessment-intervention offers an adaptation of the Barritt et al. approach to analysis, applied to a relatively large number of long interviews. Third, Lincoln and Guba (1985) suggest some specific procedures for analysis that allow for several people to look at the same data and decide whether they agree that the interpretations of the data as set forth from the study are reasonable, trustworthy interpretations.

A form, in the terminology of Barritt et al., is a striking thought or point that stands out when reading qualitative data. In the project presented here, a form may be significant to the reader of an interview because it

relates directly to a question or tentative insight that has emerged during the study, because the parent presents the point as though it is important to him or her, because it sheds new light on some aspect of the assessment-intervention process, or because it relates to thoughts that other parents have mentioned during the course of the study. A common form is a form that occurs repeatedly across interviews--essentially a theme, or a similar thought expressed by many parents.

The first step in the analysis of the final interview transcripts involved two project staff members reading through the transcripts to identify forms. One of the readers had not done any of the final interviews; the other reader (one of the researchers) had done approximately a third of them; both were very familiar with the project. They read through the same interview independently, underlining significant statements, and writing tentative interpretative notes in the margins or on another sheet of paper. After reading an interview, they discussed the interview, the statements they had identified as significant, and their interpretations. They compared which points they had considered significant and how they had interpreted them, talking through their observations until they reached general agreement on the interpretations. This provided a forum for two readers to determine whether they interpreted the statements in the interviews in similar ways. After the discussion, each of these readers typed a list of the forms that she identified in the interview, with notations of the page number or numbers where she found quotes that provided the basis for each form. In the margins of the interview transcript, she wrote the number of the form as designated on the typed list of forms. With this notation system, it was possible at a later time to retrace the steps of the analysis, from the form on the list to the statements in the transcript that led to the form. Thus, if clarification of a form was needed at a later point in the analysis, one could easily look up the statements referenced in the interviews. In addition, an independent reader could later retrace the path from the conclusions to the data underlying the conclusions, and make judgments about whether the conclusions were reasonable on the basis of the data that led to them. To further clarify the intent of the forms, we often included quotes from the interviews to illustrate the forms, so that the words parents had used to describe their experiences and perspectives were included along with the listing of the forms.

Once two staff members had read the final interview transcripts and listed forms in the manner just described, we looked for consistency between interviews. After writing a list of tentative themes (common forms--thoughts that seemed to run through many interviews), we cut apart the lists of forms from the interviews, and sorted them into groups, using the list of tentative themes as a guide. Gradually we refined these themes on the basis of how well the forms fell into each of these areas.

Once we had a workable list of themes, rules were written (in the fashion suggested by Lincoln and Guba, 1985) for each theme. Anyone sorting forms into these different themes had rules to use when deciding whether a particular form belonged with a particular theme. The researchers sorted forms from the

interviews into these themes. On the basis of this complete sorting of forms into the themes, the themes and their descriptions were further refined, yielding the themes and descriptions that appear in this chapter. Since the forms include or reference quotes from the interview transcripts, a wealth of parent quotes exist which illustrate and support each theme. Finally, another project staff member, who had neither met or interviewed the families nor previously read the interviews, read a sampling of interviews and checked for logical consistency of the analysis by retracing the steps from themes to forms to quotes in the interviews.

Table 3 presents a summary of the analysis process used with the interview transcripts.

Table 3

Summary of Analysis

* identify forms in each interview transcript
* identify tentative themes
* sort forms into tentative themes
* refine themes
* sort forms into themes
* illustrate themes with quotes
* trace audit trail to check for logical consistency

Several points about the interview analysis procedures merit highlighting. First, the process emphasizes commonalities in the descriptions offered by different parents about similar experiences. Second, several people have agreed that the interviews reflect the themes described. Third, the notations made during the analysis process make it possible for independent readers to make decisions about the reasonableness and logical consistency of the conclusions.

Overview of Interview Themes

Table 4 provides a brief list of the main interview themes. Following the table, there is a detailed discussion of the content of the themes and the relationships between the themes.

The themes have been organized into groups of related themes. Often, the parents in the study discussed related themes together. For instance, when talking about the types of information that they look for from an assessment, they often named and discussed several categories of information during one part of the interview. However, the parents did not specifically articulate the relationships between the different groups of themes. The organizational scheme represents a logical way to group the themes, and as such provides a tool for understanding the themes. The organizational scheme emerged during the effort to understand the meaning of the themes as an integrated whole, after spending a great deal of time and thought with the themes and interviews.

Anyone reading these themes and the related comments from parents should keep in mind that these families brought to the

interviews a wide array of experiences with professionals. Although they all experienced the assessment-intervention model while they were part of this project, they also received a variety of services in different settings throughout the mid-Atlantic geographical region. Therefore, the experiences they used as illustrations during the interviews did not all occur as part of this project, or as part of their experiences at the hospital where they were in the neonatal intensive care unit. Rather, they drew their examples from a broad scope of experiences. In addition to their assessment-intervention experiences in the project, most of these parents had encountered many professionals from various disciplines in diverse settings.

Table 4

Summary of Interview Themes

APPROACH TO COMMUNICATION

1. Parents look for a comfortable style of communication with professionals. They desire someone who treats them in a friendly way, someone who shows interest in them.

2. Parents look for signs that a professional is listening to them, welcoming their questions and comments, and respecting their judgment as parents.

3. Parents want professionals to have empathy for their situation.

4. Parents look for signs that a professional cares about their baby.

5. Parents look for professionals who seem to have time to talk to them, get to know them, and answer their questions.

6. Parents look for professionals who use terminology parents can understand.

7. Parents want professionals to share information about the child openly and honestly.

THE PARENT-PROFESSIONAL RELATIONSHIP

1. Parents like a parent-professional relationship in which the parent and the professional work together and treat one another as equals.

2. Parents look to professionals for expert knowledge that they do not have on their own about the baby.

3. Parents see their own area of expertise as knowing about the baby, and believe this is information that professionals need.

4. A consistent, continuing relationship between parent-baby and a professional improves parent-professional communication.

PARENTS WANT INFORMATION FROM AN ASSESSMENT-INTERVENTION

1. Parents want to learn how the child is doing developmentally: what s/he does well, what s/he does not do well, and comparison to chronological age group.

2. Parents want to learn what to do with their children to facilitate development: information about how to help if something is wrong, suggestions of ways to help their child's development.

3. Parents want to learn what to expect of the child developmentally: what is appropriate now, what to look for in coming months.

4. Parents want information specific to the needs of premature infants.

5. Parents want information about corrected age.

6. Parents want information that meets their needs: practical information that they can use in their day-to-day situation, or information that they did not already know.

7. Parents mention other categories of information depending on individual situations, such as referral to other resources; explanations about specific items during the test; a statement that developmental test results are not predictive.

FUNCTIONS OF INFORMATION

1. Information lowers anxiety.

2. Information equips and builds confidence for interacting with professionals.

3. Information enables parents to observe their baby more carefully, and to observe more about their baby's development.

4. Information enables parents to see and apply principles of development, to solve problems on their own, and to generalize to other situations with their baby, other children, and friends' children.

5. Information enables parents to see their babies as individuals in relation to development.

6. Information enables parents to match activities and opportunities to the baby's developmental level and needs.

7. Information enables parents to see their baby's areas of need and slowness for themselves.

8. Information enables parents to understand the reasons behind assessment approaches, recommendations or conclusions.

9. Information equips parents to make decisions about whether to follow recommendations or whether they agree with conclusions about their children.

10. Information helps parents feel more comfortable with the test process.

11. Information helps parents feel more confident about their parenting.

BEST PERFORMANCE, ASSESSMENTS AT HOME

1. Parents tend to prefer infant assessments done in their home.

2. Parents want an assessment to reflect their child's best performance.

Discussion of Themes in Final Interviews

Opening Thoughts

Originally, we saw our task as twofold: identifying specific components of the assessment-intervention process that parents find helpful or unhelpful, and collecting parents' suggestions for new ways of structuring assessments. Gradually, it became clear that the assessment-intervention model as we applied it worked well. Rather than making a list of what parents do and do not like, we began to redefine the task as developing a detailed explanation of the process of parent-professional interaction as it occurred in the assessment-intervention setting, and an explanation of why it works. As it turned out, parents tended not to express their preferences in terms of lists of do's and don'ts, but rather to describe what they experienced and how it worked for them.

Along with the observation that the assessment-intervention process does not reduce to a list of do's and don'ts, it also became clear that no one factor could be isolated as the one most important factor. Good assessment-intervention necessitates an effective combination of interrelated factors: good communication, good relationships, competent assessment, adequate information, and effective teaming with parents.

In addition, the interactions between parents and professionals that take place in and around the developmental assessment of a baby occur in a complex interactive situation of give-and-take, in which the parent and the professional continually and mutually affect one another, progressively shaping each other's reactions and responses. Parents observe and evaluate professionals, make judgments about them, and respond on the basis of their judgments. Similarly, professionals observe and evaluate parents, make judgments about them, and respond accordingly. The following themes and subthemes provide examples of the mutual effects of these interactions based on our project's interviews. Hopefully, you will gain some insights about how to optimize these interactions in your own assessment settings.

APPROACH TO COMMUNICATION

Parents experience assessments in the context of their relationship with the professional. They generally look to professionals to set the tone of the interactions, and then make judgments about how to react: whether to stay with this professional, how much weight to give a professional's input, how much to question and communicate. The foundation for establishing a good working relationship between a parent and a professional is in these "messages" about communication.

Parents seem to have fairly consistent ways to evaluate whether a professional is responsive, caring, willing and able to set up a helpful relationship. The major categories of evaluation that parents described compose the first group of interview themes.

1. Parents look for a comfortable style of communication with professionals. They desire someone who treats them in a friendly way; someone who shows interest in them.

We heard many statements about friendliness, tone, attitude, and establishing a feeling of comfort. One mother paid the researcher a compliment by saying "we old friends." Three other mothers described the importance of a friendly tone this way:

> "I am speaking for myself, I am definitely a people person. I deal with a lot of people so it is not hard for me to distinguish actions, a way a person talks to you or the way they react to let you know if you feel comfortable. It's the tone or the things they say that makes you feel comfortable or uncomfortable."

> "How do you think professionals and parents should interact during developmental follow-up?" "Like they were friends. Say whatever comes to their mind first, even if it is to say something like you look nice or something. Anything. The last time I saw Dr. X., he called me into his office and congratulated me for doing such a good job with the babies. That made me feel good.... He just commented me on the good job I did. And that made me feel good because he took the time to give his opinion. Instead of just doing his job he took the time to say something nice.... With me and you it was like friends. In other words, I felt you were honest

with me and I could be honest with you.... With you, when you come here you have a purpose in being here but you do it in a friendly manner... It is almost like we['re] both studying the babies all at the same time.... I don't feel like I have an inferiority complex with you."

"I think it should be a relaxed, friendly environment sort of thing where you can feel comfortable talking to the person and feel like you can open up to the person and really tell them what your concerns are and have that person be able to reassure you or maybe just to say, I could see that, but I think he has more time before he would generally have to show that skill."

One determiner of this comfortable, friendly atmosphere is having a professional who is willing to talk--to communicate well in a general sense. "The most important thing was communication, not cutting me out because I was a parent and I wasn't on the level of the provider." Parents comment on the consequences of less friendly parent-professional relationships, and they suggest their thoughts and feelings about these relationships. One mother "felt like yeah, she knows what she is doing. But I felt like I couldn't talk to her, I felt like I couldn't relate to her. But, she is coming to do the test, I'm glad she won't have to come and do it for another couple of months."

Closely related to friendliness is the importance of a professional showing an interest in parents. One researcher evoked the response, "It is like this, you ask questions as you go along, well, how long has he been doing this or something like that. It shows that you are interested in what you are doing whereas someone else who is coming out to get paid for their job and they just come in and do it and they are gone. When you try to say something to a person about so and so is doing this and you can tell that they are not really interested in it. They are only interested in what their job has required them to do."

We also noticed that sometimes the word "professional" holds a negative image that must be overcome. Parents said things like:

"You always see the professional as someone important."

"Most professionals want to keep whatever they are doing on one level and really keep you in the dark."

"I just think it is easier to talk to someone in general that is empathetic. You are more likely to express yourself to someone like that than someone who is just real professional with no personality.... Well, when I say professional I don't necessarily mean someone who is hard-nosed and distant. A professional can be all different kinds of persons."

These quotes encourage us to overcome the slightly negative edge to parents' thoughts, by going out of the way to establish a friendly atmosphere early in the relationship with a parent.

2. Parents look for signs that a professional is listening to them, welcoming their questions and comments, and respecting their judgment as parents.

> "I think listening is the most important thing. Someone who is willing to listen to your concerns and not belittle them. That is most important.... Someone who is willing to let you ask the questions that you wanted to ask."

Listening to parents is as important as talking. "Listening" includes things like accepting parents' concerns as important and valid ("When I took her to get her eyes checked...the doctor almost made me feel stupid. She made me feel like I am jumping the gun getting her eyes checked at this time. They were not very helpful."), and listening to the things parents have to say about what the baby does at other times ("If you don't listen to me you don't know how the baby is doing because I am the one who listens to Donnie everyday every time.") Here again, many parents seem to discern the cues about whether a professional wants to hear from them. As one mother said, "I usually just sit back and listen and don't talk but working with this program you ask questions and give me a chance to voice my opinion."

Just reporting parents' information is not enough to convey that you believe them. You must convey it in a way that gives it credibility. One mother reported a situation in which, "I think we had gone up to [the doctor] and he [the baby] had a bad cold. I saw the follow-up letter to his pediatrician and it stated in there that his voice sounded really weak and hoarse. And it mentioned in there that dad had mentioned that the baby usually doesn't sound like this, but it was obvious to us that the baby was under no distress. He definitely had a cold. If a baby or anyone has a cold, that is some distress. So that is the only one thing that I did not like. Dr. J. when I saw him said if a baby has a cold, there is some distress. His voice sounds ok now, so it was something that got cleared up right away. What I saw in the report is what my husband told them, what they thought, which was fine, and what they told the doctor. You see there was a situation where he said one thing, they say one thing, but in the letter they said it so that is the way it was."

Sending the message that, as a professional, you listen to and answer questions, is a specific aspect of the issue of listening. Some parents will ask their questions or express their thoughts regardless; others decide whether or not to ask, on the basis of their judgment about whether the questions are welcome; some weigh how comfortable they feel against the importance of the issue to them before deciding whether to ask their questions.

In addition to making general statements about the importance of being able to ask questions, many parents can cite specific situations that inhibit or encourage their asking questions or expressing opinions. For example, they look at whether the questions that they do ask are answered; they may feel inhibited if there are too many professionals to deal with at once; they may want a clear statement that questions are welcome.

One mother wants the professional to set up an atmosphere where she knows she can ask questions, "Like paying a lot of attention to the person and telling and if you have any questions ask, even if it's odd always ask, you learn everyday." Another decides if she can ask her question by the professional's manner: "A lot of times in the waiting room, if they walked in very hurried and they treated you like let's hurry up and get this over with, not really by what they said but by their body language. And they were constantly running in and out and I thought this is the type of person that I can't talk to. And sometimes I try and ask him questions and they give me a real quick answer. And it wouldn't satisfy me. It wasn't really answering my question. So I think I better not ask any more. I'll go to another source." This mother also determines if her questions are welcome by whether or not the professional readily answers them. She tells of one who "just wouldn't answer them. He would go off and do something, leave the room or something, and come back and just ignore your other question. But that is his personality. He has always been like that. I didn't feel like I had a lot of support there."

Another parent described the interaction between the atmosphere that the professional sets for asking questions and the parent's contribution to the process. She said that in the beginning she was not as open about asking her questions; she had many questions she didn't ask, partly because she didn't know what was going on. She was told she could ask questions, but didn't feel comfortable with herself to do it. Some of the time, she didn't know if she was ready to hear the answers. All of this seems to imply that professionals can open the door for parents to ask questions--make it clear questions are welcome and try to make them feel comfortable--but they should also be willing to wait until the parents are ready to ask them, and this may take time. As she said, "how much can you really do, how can you really do or say to somebody unless they're ready? I mean, you can say please call me or if you have any questions or problems call at any time or do you want to come and see me or--but the person that needs the help is the one that has to come forward first."

3. Parents want professionals to have empathy for their situation.

One mother of premature twins, who described how her needs had changed over the course of a year of developmental assessments, wisely pointed out that someone doing assessments in this situation should, "give a little bit of comfort, whatever, initially. And then after that you can get into the working through the development." Another mother of twins provided a very clear example of how she wanted professionals to understand her situation. She explained that, "professionals should be more understanding and look at things from a parent's point of view and a situation type thing. Meaning, because I had twins, they had told me to schedule appoints to have Ned to have a hearing test and Nancy to have her eyes checked or whatever and the boys were in school at that time, so it wasn't always easy. And I had to take both of them. Both of their tests were at the hospital and I had a hard time finding someone to go with me. It was not like I could jump on the bus or the subway with two kids. I always had to find someone to go with me. And [the hospital] would

get mad at me because they thought I was doing it intentionally but I wasn't. And after they got that attitude I never explained why I didn't make it because when people have twins or triplets it is not easy to get around. I don't think they take this into consideration."

Many parents mentioned that they thought someone who has children of their own may understand the feelings of a parent because of their experiences with their own children. This did not come across as a plea for all childless therapists to move to another line of work, but rather as a plea for professionals to try to feel what it might be like to be in the parent's position! One mother described it this way: "...I always wonder does this therapist have any children? Sometimes you get the feeling that they don't have any children of their own and they might not be able to put themselves in your place and understand how much concern there is." She went on to explain that it wasn't just that she feels better with someone who seems to empathize with her, but that she also find it easier to communicate effectively with someone who knows how she feels. "I feel like you can open up more to a person who can empathize more with your concerns and that would mostly be someone who either has children or someone who has worked for children for so long that they['ve] just seen so many parents and realize what your concerns are rather than someone who is hard-nosed and has a job and just wants to get the job done, and get it over with."

Of course, empathy becomes particularly important when the developmental specialist needs to convey information that a baby is not doing quite as well as one might hope. One mother of a baby born at 26 weeks summed up her thoughts about this situation with the words, "You have to be honest but you also have to be reassuring and optimistic and supportive."

4. Parents look for signs that a professional cares about their baby.

Another important measuring stick that parents use is to evaluate their baby's comfort with the professional. Put concisely, "Do you love babies? That['s] what my question really is." Parents observe the way that the professional interacts with their baby, and what they observe affects the way that they react to the professional and the things that s/he says. "In a way, if I see the way they are reacting to her then it affects how I feel about them." Another mother said if a professional establishes rapport with the baby, "That shows that you have an interest in her and not just in it because it is your job...It makes her feel more comfortable." She also said clearly that if a professional does not seem to care about the baby, she does not listen to their advice. When referring to one place she had been with the baby, she said, "I think the first thing about them is that they didn't seem to care about Callie. And that gave me a negative idea about them. So there wasn't anything they could correct me about."

Parents decide whether the professionals cares about their baby by looking for signs such as making supportive, encouraging comments about the baby; touching the baby; remembering something about the baby between visits; being sensitive to the baby's needs during the visit; and

remembering how the baby was doing at the last visit and noticing changes. The following quotes from the interviews illustrate these points:

> "I really appreciate Dr. X. taking time with her and you know she was really involved with Patty and she told me when she first started working with Patty that Patty was kind of special to her because she was such a little feisty thing from the beginning. You know, I loved all of the love and togetherness when it came to looking out for her well being. Everybody was real concerned about her well being and her walking and talking and growing."

> "[I liked] the common interest. The interest in him, taking time to be interested. Every time I go in, "How is Billy doing? Is he doing this, is he doing that?" And like Dr. Q. who is always asking, "How is he doing?" They want to know what he has been doing."

> "[I look for] someone who tries to get along with the child, tries to get the child on their side, to be real friendly to the child and speak to the child and try to make the child their friend and not just try to manipulate him or whatever. That is important."

> "They were not child-oriented either. They would give her a ball to get her to do something that they wanted to do and then it was time for something else. They didn't ask for it back they just took it. She stood there crying. They went on to the next thing like it was routine. I didn't like it."

Several parents described situations that suggested that they look for signs that the professional appreciates their baby's individuality, rather than interpreting their baby on the basis of risk categories and statistics. For example, one mother whose baby had been born very early and experienced many medical complications made it clear that she does not want professionals to predict her baby's outcome on the basis of his medical history, but rather to look at this individual child and how he is doing now: "It shouldn't get to be a prediction because some babies I am sure you won't be able to predict. Like if a baby weighs this or does this, but you just never know.... And I hear a lot about with his history and that is what history is, history. I still get it, well with this history.... Some people have made evaluations on him without even looking at him, based on his history he has to be this way."

Similarly, another mother, whose baby had been born at 26 weeks weighing 650 grams, did not like it when people focussed on how small the baby was, rather than on how she was doing developmentally (i.e., on the negative and on a point the mother thought was less important than other things she had noticed). She wants professionals to appreciate the progress the baby <u>has</u> made, and the areas she as the baby's mother saw as the baby's strengths--not only on the areas they emphasized from their own perspective. As she put it: "The only thing I didn't like is when people would fixate on how small she was. And that never came from you. But I got it from other people. She started out so small. I mean there is only so much she could have grown. And I didn't like it when they

would fixate on her size and not pay attention to how well she was doing developmentally.... They didn't take into account how well she was doing considering where she had started... Her progress was very, very steady. Every month she would gain a nice even amount of weight. In other words, I was so proud of her... They were not that pleased with her progress and that didn't match up with how I felt so I came away feeling kind of depressed and not looking forward to taking her again.... They didn't emphasize her strengths or what I thought were her strengths."

5. Parents look for professionals who seem to have time to talk to them, get to know them, and answer their questions.

Comments that relate to this theme include statements about professionals having time or taking time; statements about professionals who are too busy or rushed; and statements about professionals who are accessible when parents need to ask questions. For example:

> (In reference to the researcher as a clinician:) "You have put so much time into action. You didn't just come in, do your report and off you are out the door. It just so happened that that day I am worried about something or I overtalked about something, you have been patient and you have listened to me without rushing me. And you know, that was important."
>
> (In reference to the assessments done in her home as part of the project:) "It was more relaxed. I didn't feel like I have an appointment from one to two and we have to squeeze everything in."
>
> (When talking about professionals who don't have enough time:) "But me, I will ask question after question and they will try to skip around the subject. 'I have to rush over here, there is another baby I have to see.' It is something to get out of what I am trying to find out about my baby. I don't think it should be like that."
>
> (In reference to a support person from the neonatal intensive care unit who made herself accessible after the baby went home from the hospital:) "Just knowing that someone was there. In the beginning it was more important to know someone was there any time of the day, which I know is unusual but this one person did make themselves available day and night... That was really appreciated. She didn't have to do it and I tried not to abuse it."

6. Parents look for professionals who use terminology parents can understand.

Many parents state that they want information in understandable language, or that they do not like technical terms or medical terms. Technical terms interfere with communication, and may make parents feel like professionals do not want them to fully understand the information. They prefer explanations "in their own language. Because sometimes a lot of people don't understand doctor talk and the doctor or

the person may have to come down to the parents' level in order to get the point across."

One mother interprets the use of professional terms as meaning the professional must not really want her to know the information. "And then it is like they beat around the bush because you are asking them something and they are using all these professional terms. Why would he be telling me this knowing that I don't understand those type of terms because I didn't go to med school to learn those different type of treatments." She also explained what can happen if explanations are given in terms that parents do not understand: "They use medical terms. You don't know what they mean so you just agree with them. They do that a lot. And I will ask what does that mean? But a lot of parents don't know what that means so they just say ok and accept that. But they are still worried in their mind."

Another mother gave this example: "Sometimes the pediatrician give me those medical terms and I asked them to explain to me in language which I can understand the medical terms, just like in the hospital. The medical terms with the a and the b's. I didn't know what an a and a b was. Until I looked it up, because he told me he could have some a's and b's."

7. Parents want professionals to share information about the child openly and honestly.

This area includes statements that parents appreciate or want full, open, honest information from professionals, as well as statements that they do not like it when they think a professional is holding back information or not sharing an honest opinion. A mother of triplets gives straightforward advice to professionals: "Don't beat around the bush. If the kid's going to have something wrong with it, and they think it is, then say something. Don't let's find out later."

This is an area that sometimes makes professionals uncomfortable, because it is also clear that parents do not want blunt information when there is negative news about their baby, and they do not want to hear only negative news without the balance of some hope. We also know from experience, as well as from parents' explanations, that it may take some time for a parent to be ready to hear certain information.

Perhaps the best guidance came from some parents of a very early (26 weeks, 820 grams) baby. They tried to explain how to take cues from parents about how much information to share. Professionals should try to read, through parents' questions and reactions, how much parents want to hear, and then tell them that much:

> "Maybe [professionals] should ask questions. If a parent doesn't want to know, they would tell you, if they don't volunteer it. Do you want to know all the pros and cons? Ask them that and get deeper and deeper and if they say yes then go on another level until they have reached their threshold. I just think [the professional] should be more in tune with the parents to see where their threshold, where they are comfortable in saying don't

give me any more information. But I don't think it is that difficult to determine if they just do it in steps."

In another example of the way that parents and professionals can mutually affect one another's communication, this mother explained that thinking that the professionals were not being open about the baby made these parents feel less comfortable about communicating in return. "For me, the ones were the easiest to communicate with were the ones that were most genuine in their response to me."

THE PARENT-PROFESSIONAL RELATIONSHIP

Once the basic foundation of a workable communication style has been established, parents and professionals are free to move toward developing a good working relationship. When asked what they considered the ideal parent-professional relationship during follow-up with their baby, parents consistently described a relationship of working together. They respected and wanted the benefit of professional knowledge, and in return they wanted professionals to recognize and respect their expertise about the baby.

While reading about these themes, it is important to keep in mind that, within the context of this project, these parents were treated as equals and partners in every way we knew how. They were responding to their experience in this setting.

The first three themes in this section are very inter-related. We have separated them to delineate how parents see the partnership between parents and professionals in terms of areas of expertise: more technical knowledge about development on the part of professionals, and individual knowledge about the baby on the part of parents. Most often, one quote touches on all three of these themes.

1. Parents like a parent-professional relationship in which the parent and the professional work together and treat one another as equals.

Using descriptive terminology, parents talked about partnerships, working together, participation, being equal, parents and professionals listening to one another, being a team, needing input from both sides, mutual respect, and parents being actively involved with professionals. When pushed on the ideal balance of input from parents and professionals, they differed somewhat, with some parents suggesting a 50/50 split of input, some giving a little more weight to the professionals, and some giving more weight to parents. The message was consistent, though, that both sides deserve substantial input when assessing a child's development and needs.

2. Parents look to professionals for expert knowledge that they do not have on their own about the baby.

Parents readily recognize that professionals have knowledge or information that they as parents need. They look to professionals to contribute knowledge that they as parents do not have on their own.

3. Parents see their own area of expertise as knowing about the baby, and believe this is information that professionals need.

In this area, parents observed that professionals had learned something about their baby from them as parents, and that parents know things about their baby that a professional may not. They also note that they like being asked about the child's behavior and development at home.

Consider first, a group of comments from different parents on how the level of participation should be divided between the parents and professionals when doing developmental assessments:

> "I think it should be equally done. I think you need the parents' input as well as the parents needing your input."
>
> "I don't think it should be 50/50 because professionals, they are the ones that know better. But I think it should be almost half and half. Because even though someone has a degree and they know a child and they are used to working with children, some insights that a parent might have on their particular child, they're not used to dealing with 50 other kids. They're used to dealing with that one individual. But sometimes some insight that they have on the child may help in the situation. It should be almost half and half."
>
> "I think probably it would be a 70/30 type of relationship. I don't think 50/50 because there is no way that parents are on equal grounds with professionals, because there is so much that they don't know. And I think that 70% of the input would be the professional, their recommendation, what they are seeing in your child. I think that in the other 30% they should listen to what the parents themselves say their child is doing or not doing. Take those things into consideration because there are people out there that don't listen." (Although she gives precedence to the professional's input of information, this mother particularly liked participating in planning for the assessments, including providing insight about how to arrange for the baby's best performance.)
>
> "I think it should be mutual. Professionals have their ideas. Parents know more, really, because, you know, you've never had a preemie. You're learning, too. I've had the preemie; but you know the professional's side of it and I know the mother side of it. So, that helps a lot, let's put our heads together, you know."

One mother who commented on the importance of her involvement during assessment-intervention sessions also highlighted the fact that a professional can set the stage for parent participation. She said, "Everything that went on, I was a part of it, I was involved in it. Whereas a lot of time, you know, like at your health care facility, or something like that, usually you sit back and be quiet, but you asked me everything and got me involved in everything so I feel more a part of it."

Another mother emphasized that parents and professionals must listen to each other, and respect each other. She sees it as her responsibility to listen to what the professionals say about her child and to follow their recommendations, even if she disagrees with their concerns, but that it is their responsibility to listen to and respect her knowledge of the baby. "With me as a parent I have to understand and respect what they say. Even though they are going to tell me what they think, and even if it is negative I have got to respect it and take it in stride.... But if I tell you something about him, don't shrug your shoulders."

Another mother also highlighted the importance of parents and professionals listening to each other:

> "I don't think parents should pretend to be professionals. I still think that the professionals should listen to the parents because parents know the child better than anyone else. And I often think that the parents should be open-minded and listen to a professional opinion. I think that the lines of communication should be open."

Another set of comments highlights the importance of parents and professionals working together:

> "I think a professional should give you all the options and a parent should give you all the details about the child so they could form a unit about what is good, bad, helpful, stressful problems for the baby. If the two of you come together and one could give all the intimate details about the baby and the other could give more educational things about the baby, what to expect, what to enhance, you know, that type of thing, and the mother or parent can give the details of what they see from day to day with the child and how she reacts to the family, lights, noise, and music and those types of things."

> "But, both of us, the parent and the person that comes to do the test, both of their positions are pretty much important because we're helping each other out. Like I say, you come in and you're really telling me straight up the guidelines what babies should be for certain areas, and by me observing him.... But we both working together as a team. I couldn't do it if you come here and every time I say he's not doing anything different. I don't notice anything. That's not helping you at all.... We have to work together and pull together as a team to make the program work. If you comment to all the parents and they are not paying any attention to the child, it's not doing any good, not at all."

> "The parents have a lot to learn from the professionals but the professionals want to know what the parents know too, because the professionals aren't with the kids 24 hours a day and we probably see more than you would probably see. So it is good that we can both touch bases on her development. You are giving me advice and asking me what I know."

> "I would like to see a two-way relationship where they could both work with one another. Because they have to.

There is no way that one can tell the other one because the parents have a lot [of] things to learn from the professionals because the professionals in that field know a lot of things that the parents don't know. But on the other hand the parents are with the baby every day, they know a lot of things about their own baby that the professionals don't know. So they have to work on a one on one basis. Both of them have to work together."

"Well, obviously professionals are called professionals because that is what they are and they have a lot of expertise that the parents don't have. And I think that is important to remember, but at the same time it is your baby and you know a lot about your child too. So in a way I like the idea of a partnership... So I think the ideal thing would be a little more of a partnership that the parents and the professional are working together. But, obviously the parents should benefit from the expertise."

Two parents noted that the balance between a parent and a professional may change at times, depending on the changing needs of the parent:

"You're a partnership when we work together, try to get Tabitha to do things. You're a consultant when I have questions that I want to ask you."

"Well, at first authority you think of them as, this is new to you and you're blind, you know nothing about this new thing that has happened here, the prematurity. And they know everything. So therefore they are the authorities. Then, when you get the child home, and you start feeling that the child is getting bad, and then you talk with your professional. You give information and the professional gives feedback on the information you provide. So therefore you are providing them with certain information and they are giving you information that you want or need back. Because then they are more of a consultant. And then I think later on you are seeing the same thing. You as a parent and the professional are seeing the exact same things and basically--you are seeing the same things in your child, then it is more of a partner type thing."

Finally, many parents explain why they think it is important for professionals to gather information from parents about how the baby's behavior during an assessment compares to the baby's behavior at other times:

"It was important for you to ask me if she could do this or if she couldn't do that or maybe it was just because she was tired."

"I think for the parents they are with the child so they know the child the best, the most. If you ask us during the assessment is this what he normally does, we know if that is something that he does all the time or doesn't normally do. If he doesn't do something we can tell you at other times that he does do it. We know the child the best, I think."

Gathering input from parents includes giving them opportunities to try to get the baby to do things s/he will not do for the professional: "If they can't get him to do certain things, they let me do what I know to get him to do certain things...sometimes babies don't go by the flow of what they are doing so if he doesn't, they ask me little things and I tell them what to do to trigger him to do some of the things that they want him to do and it works out fine. And it helped them too to see that babies don't always go by the guidelines or when you want them to do things or whatever."

One mother tempered the weight that she would give to parents' information about a baby when performing an "objective" assessment. She thought that most parents know how much their children are able to do, and that most parents want their child to do well during assessments. Despite this, she was unsure of how much a parent's report should be added to an "objective" assessment, thinking that the results are more "objective" without parent report. "I guess they're equally important, but I don't think too much stress should be put on what the parents think. There are some parents that would say, oh yes, my child is superior, he can do this, this, and this. And you can tell obviously, that they can not."

4. A consistent, continuing relationship between parent-baby and a professional improves parent-professional communication.

In this area, we heard comments about the developmental specialist who did the assessments getting to know a parent and baby better over time, about the advantages of having a series of assessments over time, and about the disadvantages when a different developmental specialist began to work with a family at the 3 month assessment (after a hospital observation and a Brazelton Assessment with a different clinician). We interpreted comments like these as arguing for a consistent relationship between the same clinicians and parents over time, whenever possible, at least for the duration of a year-long project.

Other points in this area emphasized the advantages of having a sequence of assessments: parents are able to compare and see the baby's progress, and it takes more than one visit to learn what you need to know about development.

Even with a consistent relationship from the hospital observation through the 12 month assessment, one researcher noticed that, in 2 cases, she did not establish a relationship with the depth of communication she reached with the other families she worked with. She felt that one of these mothers was gradually beginning to trust her and open up, but that 5 assessments with the related phone calls and interviews had not been enough to establish full trust. Another mother had difficulty responding to the questions during the final interview, and the researcher wondered whether the reasons were related to not establishing a trusting relationship. These observations do not argue against pairing parents and clinicians consistently, but they do point out that even with a consistent arrangement, it may take a long time or be difficult to establish a close working partnership.

One mother clearly thought that a developmental specialist could meet her needs more effectively if she did several sequential assessments. She explained the process of getting to know a parent and baby's needs better in this way: "The first time she didn't know what it was, what we are doing with Donnie. But then the second time that I can tell what you are doing was much much better, because you know what I wanted, you gave me a lot of suggestions and the third time it was better than the second time like you gave me suggestions what to do with Donnie and do it better better than before."

Another mother noted the importance of a consistent relationship in a different way, emphasizing the difference in her contribution to the relationship. "I guess it is the relationship I have with that individual. Like, I might feel more comfortable with Cathy because she came every week and I knew her better. I think it depends on the feelings I am getting from whoever I am dealing with. With [my pediatrician], I am very proud of Debbie and with him, because he is really in charge of her care, that I think I tend to make more of a effort to bring him up to date because he is really responsible for her care. Whereas [with some other doctors] I just don't feel that same connection."

This same mother had experienced a change in researcher before the time of the 3 month assessment. In addition, the researcher identified some developmental concerns about the baby when she did the 3 month assessment. Although they were communicating comfortably by the time of the final interview, the researcher had felt that this mother had had a very difficult time hearing the concerns about her baby, and that she had not been comfortable with the clinician during the early assessments. The researcher's notes indicate: "I asked her if she felt like difficult information would have been easier to accept from me at the 3 month interview if she had met me at the time of the Brazelton and if she had met me in the hospital. In other words, if we had had two contacts prior to the 3 month assessment... And she felt like, yes. If she had met me in the hospital and had been meeting me as the person identified as the someone giving her suggestions and monitoring Debbie's development, meeting me as a supportive person rather than meeting for the first time as a person giving her feedback about Debbie, she felt like that would have helped in terms of how she would have accepted the information that I shared with her."

PARENTS WANT INFORMATION FROM AN ASSESSMENT-INTERVENTION.

Parents offered general comments about their need and desire for information, such as this one:

> "I still like it when the professional comes to me and tells me how his is doing, how he's progressing. Sit me down and talk to me--don't just say, "Billy's ok." Sit down and talk to me. Have Billy's case history in front of them.... I am supposed to know, I am the mother."

When planning with the professional for the first assessments, parents had a hard time listing the information that they wanted to gain from the assessment. Retrospectively,

however, they easily listed the categories of information they found helpful. These include the following:

1. how the child is doing developmentally: what s/he does well, what s/he does not do well, comparison to age.

2. what to do with their children to facilitate development: information about how to help if something is wrong, suggestions of ways to help their child's development.

3. what to expect of the child developmentally: what is appropriate now, and what to look for in coming months.

These categories cover basic developmental information, standard fare in the results of developmental assessments: how a child is doing, including both strengths and weaknesses; how the child's development compares to his or her corrected age; how to help the child's areas of developmental weakness, and to facilitate development appropriately; and what is appropriate to expect of the child at the time of the assessment and in the near future. These areas of information build the foundation for any developmental intervention that the parents will implement, and equip them to make more informed observations during the next few months.

One mother explained that she looks to professionals to tell her if her concerns about the baby's development signal an actual delay or if he has more time to gain the skills in question. "Well, I guess when you see it and you start to be concerned about a certain area and you begin to think, am I being overly concerned? Is this really still ok or should I be concerned about this? And when you have someone who has worked in this area and knows and has observed children this age and what they should be doing and can tell, for goodness sakes you should be doing this, then that is the difference. You can be sure that you should be getting intervention or you can feel more comfortable that he has more time to do it before it is considered a delay."

Parents whose children evidenced developmental delays wanted a delineation of the delays, with some indication of how significant the delay was at that time. "So, even though it shocked me sometimes, I liked it when you told me where she was both in motor skills and intelligence. Because it motivated when you told me when she wasn't doing so well in one area, it motivated me to work on those areas." (This retrospective comment was particularly significant because, at the time that she shared information with this mother about the baby's delays, the researcher thought the mother really did not want to hear about them.) At the same time, another mother whose child showed some special developmental needs agreed that they wanted to know about the problems and what to do about them, but also pointed out that the assessments "also helped because you can see how your child is doing and the areas they are doing well in as well. There is encouragement in some areas, it is not all negative. The positives helped a lot. It is an individual thing anyway. What matters is that they're progressing. It is helpful to see that."

It almost goes without saying that information about developmental concerns must be accompanied by suggestions about ways to address the concerns. "...if there any negative

results in the testing, you are told what you can do to help it." Another comment: "Probably the most important thing for me are the suggestions about Brenda's development. These would be your assessment of how she is doing and suggestions of how to help her develop. That has worked real well." And: "If he's not doing what he should they should give advice on what to do to make the baby develop a little faster or whatever."

"Looking back on it, it wouldn't of helped me if you came and told me, 'Debbie you are testing at 2 months' when she was 4 months old,' if you didn't give me something to work with, because then it would of been too discouraging and negative. In other words, it is good to know where your child is, but then what? What can you do if they are falling behind in certain areas? And I think that is really important because it is very hard to hear that your child is 4 months old but she is only testing at 2 months there.... It is hard to get bad news. I think it is just natural, but I think that I quickly appreciated the main point of your message which is let's work on these areas."

Several parents offered examples of the kinds of suggestions that they had found helpful:

> "The advice that you gave me was working with her on different things, putting things in a cup, stacking things. I started working with her on that. Just talking to her a lot and she started to repeat everything that I was saying."
>
> "[It was helpful] when you referred me to books, toys, games, little things to do to play with her."
>
> "When [she] first started to do the assessments, he was real tight and she showed me how to improve his posture. He was a little tight in his muscle tone, I guess. And she showed me put him on his side with the blanket behind him, rolled up behind him, and have him sleep on his side. That was helpful. Just little pointers like that."
>
> "I have learned more about how to take care of her, but I get more out of what I can do for her, how to do it, what kinds of things to do and buy, and how to work with her."

Finally, one mother made the point that she felt more of a need for developmental suggestions at the beginning (in the hospital and when the baby was first home). At those times, she knew less about what to do with the baby, and the baby had more developmental problems. (This is the same mother that made the researcher wonder whether she was wanted or not when the baby showed some early delays. Looking back, the mother said she wanted the suggestions even more at that time than later.) She said, "Well, I think it [the assessment-intervention program] affected me a lot, different ways at different points depending on how she was doing." At another point she said, "I would say probably in the beginning when she was a little bit further behind that it was much more important to me at that point to find out what to do with her. I think also that later on in the study I was much more

confident about her. I could see myself the progress she was making as she got older and started crawling and started sitting up. In other words I didn't need you quite as much to tell me, 'This is what she should be doing,' because I could see it. Whereas earlier on when they are infants and they do so little, you are more in the dark. So I would say earlier on the suggestions were more important, although I liked having them all throughout the study." She also said that she had wanted developmental intervention earlier, when the baby was still in the hospital. "I wish there would have been intervention from professionals earlier on, starting from the moment she was born.... In other words, what can I do to help my baby now? And I wish that they had had suggestions from other parents, you can go in there, you can handle your baby, you can sing to the baby, you can make tape recordings, you can massage them. In other words, that is when I really felt lost, is at the beginning and there was no one there to tell me how I could help the baby. I had to really figure it out on my own."

4. information specific to the needs of premature infants.

5. information about corrected age.

This, too, is not surprising: parents of premature infants need information about the special needs of premature babies. As one example, a mother explained, "And there are a lot of things I didn't know, like, because AJ won't hold his own bottle. The doctor at the follow-up clinic said, well, maybe it is the type and texture of the bottle that he doesn't like. And I said, what do you mean? and he said, well, with all of the things that AJ had on his body when he was a preemie--clothes, monitors, things going down his throat, they are very sensitive to feel and touch.... And I have a smoother one now. So that was very useful. I never thought of anything like that. Nobody would think of something like that."

Another point of information about premature babies came up repeatedly: the need to understand corrected age, so that they compare their babies to other babies of the corrected age rather than the chronological age. Sometimes it took several conversations before parents fully grasped the idea of corrected age. As one mother said, "it took me a while for it to make sense." It was, however, a concept that parents used often, and it changed the way that they looked at their babies, as these quotes illustrate:

> "A lot of times I do [still use the adjusted age], but it wasn't as important as it was earlier in his life, when he was like 6 months old, a full-term baby can sit up--at 6 months old. He couldn't. He just laid there. And a lot of people got worried about that. But I thought, he is really 4 months old. And I would feel better about it. I would calm me down."
>
> "...it wasn't that Ellen was too slow, it was that Ellen was too early. It is going to take a little more time for her to develop. There were times that I thought that Ellen is not doing this and I tried to compare her to other children."

6. information that meets their needs: practical information that they can use in their day to day situation, or information that they did not already know.

7. other categories of information depending on individual situations, such as referral to other resources; explanations about specific items during the test; a statement that developmental test results are not predictive.

These two points demonstrate the importance of listening to the informational needs of individual families. Parents are not satisfied if they hear only information they have heard before; they want suggestions that work within their individual family situations; they may have individual desires for particular information based on their needs and the needs of their babies.

One mother emphasized the importance of hearing that the test results are not predictive, saying, "It is very hard to hear that your child is 4 months old but she is only testing at 2 months there. [This was in relation to corrected age.] It kind of shocks you and scares you a little bit. But that is why I think it is important also to point out that it is not predictive, that is just what she is doing now.... always emphasize that in the same breath that you are saying she is a month behind in this. Which you did, really. But it is hard to accept when someone tells you your child is not doing well. And so the professional has to make a big effort to reassure the parent that it is not predictive. You can't say that enough is what I am saying."

FUNCTIONS OF INFORMATION

Effectively communicated information is critically important to parents because it helps and equips them in specific ways. These areas, which parents described and delineated, are perhaps more helpful in planning for the information that parents need than the lists of information that they cited, since the functions of the information suggest more specifically the sorts of information that parents find useful. The themes in this section set forth some of the reasons that detailed and abundant information is so important to parents.

1. Information lowers anxiety.

Information from the assessments helped parents to worry less. This seemed to be true both for parents whose babies did well developmentally almost from the beginning, and for parents of babies who showed some developmental concerns. Parents of babies who consistently did well developmentally were, of course, reassured, which was important after their babies' worrisome beginnings. Parents of babies who showed developmental concerns worried less when they knew more about what they were dealing with and when they were equipped with strategies to help their babies.

Professionals are in a position to offer information parents need in this area because of their knowledge of appropriate developmental expectations for different ages, which is knowledge that parents often do not have on their

own. In this vein, one mother commented that having someone come to do the assessments "has just eased up the whole burden of wondering how these babies are going to develop." Another explained that, "it would of been pretty hard to have brought Brendan home from the hospital and not of had anyone interacting with him and helping to assess him at all. That would have been pretty hard to just leave the hospital with this infant who was born so early and has potential to have so many disabilities or problems or delays. To leave the hospital and be on your own, that would have been pretty hard. It would have been pretty scary. I think it was really a good thing to know that someone was going to come and check up on you every few months. I think that really gave me a feeling of confidence." A third mother put it this way: "I think one thing is just being able to talk to someone outside. It takes someone outside to let you know that she is ok.... I didn't know what to expect. Is this normal with kids when they do this or is something wrong with her?"

Two parents whose babies experienced few developmental challenges described their reactions of reassurance this way:

> "It was a lot of reassurance learning about your child's development. There are a lot of helpful approaches too, like being gentle very early on, putting him on his side to sleep is the best thing for him, don't put him in a walker. Things like that, especially with being with a new parent, that were really, really, helpful."
>
> "She developed but at the same time I knew these things were going to take place and I was prepared and reassured that things were beginning to happen, you can see them starting, whereas if we didn't have that support and these were things we didn't see then you question if she is ok and you would worry unnecessarily."

Two parents whose babies experienced more developmental challenges described their reactions of less anxiety this way:

> "Well, a year and a half ago we were more anxious. It's like, we wanted to know what the long-term meant, and of course nobody knew. And once we realized that we couldn't get long-term answers, then we settled down, and what do we do next? I think the study and everybody else at the clinic, basically led us by the hand as far as this is what we should be doing... This is what you should concentrate and do for your child."
>
> (After stating that their biggest challenge was "the unknown":) "I also had a good idea of what could happen and I was prepared for it. They took care of me emotionally as well. I was still scared but I was prepared. I prepared myself for even 6, 9 months down the road, what we could expect.... It helped me with myself a lot. Initially your first response is, there is no way if I have this child that is going to be handicapped, and I can't, is your first thing. Slowly it becomes I can.... It is still not easy but you learn to accept it that it is a possibility. What helped was knowing that we had these people available to answer questions, and the other was they told us that there were many outside communities that can help... You learn to

understand that just because they are handicapped in one area doesn't mean that they are in another and they may even excel in another area because of their handicap. It helps you accept it. And in watching Leslie because I was seeing it in her. As she was growing I could see how she was doing so well in certain things and how she wasn't in other areas it didn't bother me as much."

2. Information equips and builds confidence for interacting with professionals.

Information not only helps parents with their babies, it also equips them and therefore helps them to feel more confident about their interactions with professionals concerning their babies.

One mother explained how her feelings about professionals had changed during the course of the project. She said that, in the beginning, she saw professionals as authorities. "But now the more feedback I get the more I understand, the more I feel the professional is a consultant with both experts on that one particular child. You begin to understand them, but you don't feel that they are talking over your head." "If you were given advice by a professional that didn't make sense, tell me what you would do." "Well, at first I probably would have accepted it and gone home and worried about it anyway, but now...now I think I would question them and ask them why they want me to do this, and whether they have a reason for giving me this advice." ... "And what brought about the change?" "I think the program, dealing with Katie, and knowing Katie, and what to expect from her made me realize that I can talk back to them."

3. Information enables parents to observe their baby more carefully, and to observe more about their baby's development.

This section includes examples of observations parents were equipped to make with information that they gained from assessments, and direct statements that developmental information helped them to observe their babies more carefully. For example, one couple made reference to information about areas where their baby was doing well and where he was weak, and they said, "We could see things that we might not have been able to pay attention [to]." Another mother said that the assessments had made her "much more aware of the development of [my] child. If there was no coming out by--I don't think there would have been a awareness of what was going on in the development. There wouldn't be any." This mother specifically noted that learning about what developmental accomplishments to watch for in her twins "kind of makes you look forward to the next time or the next point in which the baby reaches that goal. And a lot of times when you were here on a certain visit, it wasn't a week later when they [did] one thing that, you know, didn't do while you were here. So it's something to look forward to in that."

A very articulate mother explained how information from the assessments equipped her to observe the baby with more understanding of what she was seeing developmentally. "Well, there is nothing in the books that tell[s] you about quality

of movement, the levels of play, those kinds of things were very special to me. I know that if you do this then the next step would be to do this. But there was that interim part. The books tell you that she is going to do this at 3 months and this at 6 months, but what about the interim like how it emerges, emerging skills were interesting to me. Like how this would lead to that. I became a lot more aware instead of waiting until the event happened, I would spot it before it happened which was special to me because I really watched her develop more.... I felt closer. Much closer because you can really see her progressing on a day to day level instead of 3, 6, 9 and 12 month levels. With the preemies you are thinking about it everyday, and if you are more in tune with it, you can pick up and it really makes you feel good to see them every day learning something."

4. Information enables parents to see and apply principles of development, to solve problems on their own, and to generalize to other situations with their baby, other children, and friends' children.

When parents see the principles of development in such a way that they can apply them on their own in situations that differ somewhat from the assessment-intervention sessions in which the clinician presents the information, the learning affects their children much more broadly, and enhances their own competence as developmental observers and interventionists. When this happens, the information that the clinician shares has a broad impact, and the parents are empowered.

One mother conveyed this idea of generalized information in a broad sense when she said, "It just made me a more of a rare parent. It made me understand, I guess an educator would know a whole lot as far as a baby is concerned. You gave me a lot of insight that I didn't have with my first child. It made me understand Katie more. And in turn that made me understand [her sister] more. That made me understand these children in general a whole lot better." Another mother gave an example that illustrated that she had grasped the idea that the test items convey an underlying concept about development, that she can observe in other contexts: "Like now, with Jerry. He's not stacking blocks and things like that. But you see that he does it with other things, and you see that he's got the potential to do it with other things, even if he doesn't do it with the things that you have."

5. Information enables parents to see their babies as individuals in relation to development.

Several parents explained that information they gained from the assessment-interventions helped them to appreciate their child's developmental individuality.

For one mother, this meant learning that children develop at different paces, but the different paces can be fine for individual children. "When you see a child, like you can have three children that are all exactly the same age, but yet one may not be walking, the other may be walking and running and talking, and the other may be in between. But you can't take them three children and compare them, you just have to accept

each child for an individual person, just accept them for what they are."

For another mother, learning about the developmental capabilities and needs of her baby meant realizing that babies are more responsive and capable than she had realized, and that her baby needed her time. "You made me realize that Ellen needed my time. A lot more of my time than I expected to give a child when I first had Ellen." "Though I never said anything about it." "No, you didn't. But you showed me that Ellen needed my time." She began to see her baby "as a person, individual. Babies were considered--you feed and dry them and they go to sleep. You don't have to play with them, they don't understand what is going on, they don't know who you are. The definition of a baby changed some within. Somewhere in there a baby is a person whereas before a baby is a baby and not capable of doing anything."

6. Information enables parents to match activities and opportunities to the baby's developmental level.

Parents used the information from assessment-interventions to help their babies develop at their own developmental levels, to address areas of developmental need, and thereby to facilitate their babies development.

Specific suggestions and developmental information helped one mother challenge her baby a little more than she would have, and also be less protective. "I think a lot of parents hold back because they are preemies and they won't initiate a lot of things like games you told me to do or things like that because they don't want to seem like they're pushing the child too much. In fact, it really helped, because with her the little things like clapping hands and I bought her a little barrel with the different shapes, and the keys, she loves putting things in something and then taking them out. I think all those little things are things parents should be aware of. And the child is not as weak as you think they are."

Another mother adjusted her expectations to ask less of her daughter, commenting that without the developmental information that she gained from the assessments, "...not knowing, I would have forced her to do things before she was ready." She went on to explain in detail that she had learned the importance of learning to read her own daughter's cues, and then to match her interactions as a mother to the needs of her daughter. "I think by sitting down and having the confrontations with the parents after you have done the assessment with the child, it helps them to understand and develop with the child, because I also think it is important that the parent and child develop together. And when you have a child that is premature it's a situation where you are together but separate. You together but you can hamper the child's development because you want to keep them from so many things and you want to protect them....I know what I am trying to say, but I don't know if you are following what I am trying to say--you don't expect more from a child than a child is capable of giving you. That you and the child are on the same wavelength and you are developing slowly together at the child's pace. I mean you can help by working with the child. For instance Ellen and I will go for walks and recite our ABC's. I mean, I don't expect, we have been doing this for

awhile, for Ellen to do this herself. You are developing together, you are doing things together, you are working together, and on the same wavelength, bonded together, but not expecting a lot more than this child is capable of doing.... I say developing together meaning that you move at this child's pace. Meaning that you don't expect anything more from this child than this child is capable of doing at that point."

Another mother offered an intriguing description of how she applied the subtle developmental information that she gained from the assessments, in this dialogue with the researcher: "If you saw something happen, starting, you can see where they are and what they are ready for or what they will be ready for soon.... And with toys, I would introduce toys for a skill that was emerging instead of waiting or giving it to her before she was ready." "How could you tell that the toy was too far ahead for her?" "If she wasn't interested in it whatsoever or didn't seem to be doing--or if she was interested maybe it was something else that interested her like the colors or something but not what the function was." "Would you have know that before?" "No." "How would you have known to make that distinction?" "Just watching her play and listening to your comments on it helped me to make that distinction.... After two or three of those you kind of pick up on that. I just followed through myself and made my own assessment by watching her play on a day to day basis."

7. Information enables parents to see their baby's areas of need and slowness for themselves.

Early interventionists sometimes feel frustrated because they think that parents have a hard time accepting observations that their children show developmental delays. Somewhat unexpectedly, we discovered that, when equipped with developmental expectations for the upcoming 3 months between assessments, parents began to observe delays for themselves. Then, when the developmental specialist returned for the next assessment, she would be in the position of confirming a parent's suspicion about a delay, rather than presenting the observations without warning to the parent. One of the best descriptions of this process came from a mother whose son began to show motor delays toward the end of the first year. She said, "...and you told me some things to expect the next time you came back. And when you came back the next time I knew that he wasn't doing some of those things. And I knew that he wasn't making any progress or showing any signs of starting to do those things.... I think it is definitely better because you kind of got this sneaky feeling anyway and all you are doing is confirming something that you suspect. So you are really prepared for it more so if someone says to you, your child should be crawling by now and you really thought that a child didn't start crawling until he was 11 months old. It just hits you all of a sudden. And you start thinking that all of this time you could have been working with him on this skill in some way or another. And then you feel really badly that you haven't done something maybe that you could all along."

8. Information enables parents to understand the reasons behind assessment approaches, recommendations or conclusions.

Parents gave examples of positive reactions to presentations of the reasons behind assessment items, recommendations or conclusions. They also offered direct statements that parents want to know the reasons behind assessment items, recommendations or conclusions.

One mother advised, "Give the parents a chance to express themselves even if you don't agree, let them voice their opinions, and then tell them why you disagree with what they are saying, rather than telling them no. Give them the reason for why they feel that way."

In relation to descriptions during test items, another mother said, "You were always really good about telling me what you were looking for whenever you were doing something with Brendan. Even if it was obvious, especially when it wasn't obvious what he was supposed to be doing. And that was important."

A third parent made it clear that a simple statement that her child was doing well did not satisfy them. In reference to a place they had visited with their baby, she said, "If they had done similar things that you had done with the Brazelton and showing us what Ellen is capable of doing. I mean they told us that Ellen looks great and she is beautiful but we hear that all the time but just show me."

9. Information equips parents to make decisions about whether to follow recommendations or whether they agree with conclusions about their children.

Closely related to seeing the reasons behind assessment items and conclusions about the baby, information equips parents to make decisions about whether to follow recommendations, including whether to have assessments in the first place. Many parents made it clear that they were aware that they ultimately made the decisions about what to do with their child, and that having a full understanding of the suggestions from the assessor equipped them to do a better job with this task. Generally, if parents had any reservations about a suggestion for their child, and if they did not understand the reasons behind the suggestion, they just did not follow it. Here are perspectives on this issue from five different parents:

> "And if I don't feel there is a benefit because I don't understand it, then it's not for my child."
>
> "And, I think that parents will make their own decisions anyway, even though someone will say 'don't use this,' or 'we recommend you not use this.' And the parent is going to do whatever they think is best."
>
> "I like this better because there is a reasoning behind things.... I just like having reasoning behind things. I can listen to anyone's opinions as long as you have some grounds to stand on. I want to hear reasoning why it should be and if I am doing something wrong I might change the way I am doing things."
>
> "I think I would rather have the consultant type person than the authoritarian who comes in and says you got to

do this or else. I think the consultant is the person who will lay the facts out before you and let you make a choice."

"One of the suggestions [was to dance with her] and that would have been fine for a baby who is not on oxygen and on a monitor but how are you going to take her and dance with her a little bit. That was ridiculous. I don't have time to do that. Things like that. Yours were a little bit more specific. When you say Brenda needs to tone her abdominal muscles, they are weak. I think about strengthening her grasp and testing her pincer grasp... I have some experience in the medical field and I couldn't find a medical reason for this and I am trying like crazy to find a logical reason for it and I just couldn't do it. So I decided that I am just not doing it."

10. Information helps parents feel more comfortable with the test process.

Assessment can provoke a lot of anxiety for a parent. As one mother put it, at the beginning, "...you are not exactly sure what is all this testing, what is it? What kind of things are you doing? But afterwards you get the gist of what's going to be going on. And then you feel more comfortable with that too."

11. Information helps parents feel more confident about their parenting.

Having a premature baby can shake the confidence of veteran and first-time parents alike. Getting some information about the baby's development and how to match interactions to the baby's developmental level can provide one part of the process of bolstering their confidence about parenting. Some examples of this reaction include the following:

"It freed me to let me do what I wanted to do with them. Nothing is impossible, that is what it freed me to do and that there are no paths that they couldn't do. But I knew that there were but I wasn't afraid to try and see."

"I think it had a lot of meaning for both you and me because me and my daughter have learned a lot of things from you and you have learned a lot of things from my daughter. I feel more confident, more good about everything."

"It made me look at things in a lot of different ways, things that I do for her can be a learning experience for her too, instead of just doing it with her."

According to another mother, knowing that your level of knowledge about development and how to facilitate it is greater than most people's knowledge about these things, "that makes you feel like you're doing that much more for your baby." Knowing that you're doing the best you can with your baby brings back the self-esteem damaged by the guilt of having a premature baby. "Just doing the best you can with your baby. I mean that brings it back. Just doing the best

you can and loving you child." Part of the professional role should be to "make the parent feel more adequate in handling the baby and feeling more secure and confident about dealing with the baby." Professionals should do this by both giving affirmation about the things the parents are doing well with the babies, and teaching them about other things they can do.

BEST PERFORMANCE, ASSESSMENTS AT HOME.

1. Parents tend to prefer assessments done in their home.

2. Parents want an assessment to reflect their child's best performance.

The model for this project allowed for assessment-intervention sessions to take place either at home or at an office, according to the parents' preference. Almost always, parents chose assessments at home. Occasionally, later in the project when the parent and baby had already established a relationship with the developmental specialist, the parents chose to combine the developmental assessment with an appointment for medical follow-up, and the developmental specialist met the parent and baby at the office at the time of their other appointment.

Sometimes parents noted that doing assessments at home is more convenient for parents, and may increase their rate of participation, like the very honest mother who said, "And I think it was very nice that it was all done in the home. Because I have noticed that sometimes I just got so tired of going to all the different appointments, that I would just not go unless someone called me and said you are a month overdue for this visit. Whereas you just called and said, 'Let's set it up, I'm coming.' So, if I would have gone somewhere else I would have missed half of them."

Almost all parents, including the one quoted above who mentioned the convenience to her, noted that doing assessments at home helps to maximize a baby's performance, which is closely related to the second theme in this section, which is that parents want an assessment to reflect their baby's best performance. Parents generally thought that their baby was more relaxed, less distracted, and more comfortable at home. In addition, doing an assessment at home makes it much easier to schedule at a time that is good for the baby, planning around naps and feeding schedules.

> "He would be more relaxed at home. If he did it any place else, he might not do as well."
>
> "...the school does not test Matt, they go by your test because the fact that it is done here in the home, it is done at his best time, it is going to give a more accurate account, and there they have to come where they can schedule it, when there is a free space available, whether the babies are ready or not."
>
> "It was very nice to have someone come to the house and I think that is important because a lot of times when I would take Debbie to a office, it was a new environment

and I am not quite so sure she acted the same way at the [office] that she would have acted if she were just here with you and me in her own house. So the fact that you came here and I thought you got a much better idea of what she is doing than when I took her to [the office] because she was in a strange room and very fussy and cranky."

One mother who cited not having to travel a long distance as one of the advantages of doing an assessment at home provided this graphic description of an experience that made this point clear: "With a 5 1/2 hour ordeal from the time I left the house until the time we got home. It was just wild! No parking down there [so] I had to take the subway. By the time you get there they are already burnt out. And then to try to do any test on Brenda would have been futile at that point. She sat with the physical therapist, but I wasn't sure how much the physical therapist was really seeing as accurate."

MODES FOR PRESENTING INFORMATION

Unlike the other points discussed in this chapter, this category did not result in any consistent themes across families. No one particular mode of presentation was mentioned consistently by the parents in the study, probably because adults have individual learning styles. Many parents did make comments about preferring written, or oral, or demonstrated information, or some combination, but the preferences that they noted differed across families. Following is a list of presentation styles that they mentioned.

a) written reports supply a helpful record that parents can refer back to.

The parents in the project always wanted written reports when asked, but they did not consistently talk about reports during the interviews. Those who did talked about them as a reference they re-read and used to remind themselves of information, notice the baby's progress over time, or prepare for appointments with other professionals. Several parents mentioned that they planned to save the reports to show them to their child when the child was older.

"I like to have it because when I read through it and it helps me see what different things they can do at their age and to look and see how far they have come and how far I have helped them come through having these tests."

"I read them all. I retyped them all and put them in a notebook at work. You can see when she gets older how she was. I retyped them to assure myself that I was reading them." (This was from a mother who was not interested in books--she wanted to hear information rather than read it.)

b) "books" received mixed reviews. Some parents look for extensive written material, others find it hard to relate this

to their own baby, or need the information put in perspective for them.

> "A lot of books that you told me to read I really intended to. I am not a reader. If you think it is important to me I would rather that you just told me."

From a mother who read a lot: "You read up on the developmental stuff too, didn't you?" "Yeah, but not as much because I did away with those books because I got more out of the assessments then out of the book, which is interesting because on the clinical side I got more out of the books than I did out of the doctors. I had to resort to the books as a place to start."

> "That is really important and like you said the level of play, being able to play with an object in one hand initially verses the next step which is to play with an object in both hands. That would have never occurred to me. These things were very important for me to learn. You cannot get that in books."

> "I would say it is good to read books on the subject but remember that they are going to give you a lot of information that might not pertain to the baby and try not to dwell too much on future problems. Just take it one day at a time. Just because it says something in the book that your baby is at a much greater risk of having all these problems, it doesn't mean they are going to happen. And if you let all those things influence you too much, then it just doesn't help."

c) watching assessments provides information about development and developmental activities.

> "I am a part of everything in her development. I am telling you that Ellen can do this, you see her do it. I am sitting here and I can actually see Ellen with the puzzles, with the blocks, and you there as a proud parent glowing, my child can do these things."

d) some parents mentioned demonstrations of activities, or diagrams or pictures to explain intervention activities.

e) some parents mention simultaneous explanations during test items and demonstrations of activities.

> "Whereas with you, you showed us what Ellen was capable of doing. We talked about things and saw things, as far as what she is capable of doing this time and the next time. And we are able to compare each visit. It is different. It was more informative. I enjoyed it a lot more. We felt like we were a part of it."

> "All the stuff, you explained to me and showed it to me and then you explained it to me again to make sure that I knew what you were talking about. I understood it from there."

Chapter 4

IMPLICATIONS FOR PRACTICE

Reflections on Themes in Final Interviews

Reading through the summary of interview themes in Table 4 leaves several striking impressions. First, the number of themes suggests the complexity of interactions between parents and professionals in the context of an infant assessment. Second, the nature of the themes makes it clear that parents do not express their preferences in terms of lists of specific things professionals should include or eliminate in the structure for assessment. Instead, they experience an assessment as a relational interaction. Third, the themes suggest definite implications for the assessment-intervention model. Fourth, we have some valuable information about the process of parent-professional communication. All of these impressions hold clear implications for early intervention practice and research, particularly in light of current developments in the field with the implementation of Part H of P. L. 99-457.

The complexity of the interactions that take place between parents and professionals during an infant developmental assessment means that there are many demands on developmental specialists who aim to be sensitive to parents and provide an optimum intervention. In addition to performing a good assessment technically--with organized materials, well-rehearsed administration techniques, and astute observations of the baby--the person doing an assessment must remember and apply many principles of communicating effectively and sensitively with parents. There is no one essential characteristic that automatically makes a good assessment-intervention, but a complex and inter-related group of characteristics that must occur during any one assessment-intervention. While this makes the job of the developmental specialist exciting and challenging, it also requires a great deal of skill and experience.

The observation that parents experience assessment-intervention as a relational interaction forms a part of the complexity. This does not come as a surprise, and in fact it supports one of the original principles of assessment-intervention. Retrospectively, however, it seems that as researchers we thought that once we had the principles clearly in mind and deliberately implemented, we could move on to identifying specific practices that make or break the model. One of the clear messages of the project is that parents do not express their preferences in lists of do's and don'ts. Instead, they describe relationships and communication, because that is what they experience. This has implications for both early intervention practice and research. Parents can fill out a questionnaire, order items in terms of priority, and complete other similar tasks, but when asked about their experiences, they do not think in terms of lists and discrete choices. They think in terms of descriptions of their own experiences. What they are looking for is not so much a model of intervention that is structured in a particular way, but for knowledgeable people who will listen

to them and talk to them about their child in a way they can relate to.

One other point deserves mention here. The parents in the project brought with them a wide variety of backgrounds and experiences. While the model of assessment-intervention and the style of questioning respected and valued these individual differences, the interviews still yielded a striking array of commonalities. Parents may differ in terms of specific items of information that they need, the particular terminology that communicates clearly to them, or the values with which they interpret some of the assessment results and recommendations. Nevertheless, in a positive relationship with a professional, within the context of mutual participation and appreciation, parents have an opportunity for a meaningful exchange of information that meets needs that supercede these differences.

Implications for the Assessment-Intervention Model

Another message of the interview themes is that the assessment-intervention model "works." Although the project did not measure the effectiveness of the model in terms of differences in child progress or quantifiable differences in styles of interaction between parents and children, the comments that parents shared generally support the principles of assessment-intervention. In addition, the "functions of information" that parents delineated are quite exciting. Parents were able to describe how the developmental information that they gained from their experiences in the project changed and informed their responses to their babies' developmental levels and needs, and how the information and perspectives that they gained shaped their comfort with assessment and their interactions with professionals.

Essential Points of the Model

"The assessment-intervention model" refers to an approach to developmental assessment that incorporates:

- pre-assessment planning (Appendix B or Appendix E),
- an assessment-intervention session guided by the Checklist for Assessment-Intervention (Appendix D) and
- a follow-up contact with the family to clarify the assessment results and respond to further questions and concerns.

These components are implemented with the principles of assessment-intervention in mind:

1. Find out what understandings, expectations and needs a family brings to an assessment. These set the context for parents' reactions.
2. Aim to establish a caring, comfortable relationship between professional and parents, with contacts

before, during and after assessments. Convey that we care about both babies and their parents.

3. Provide a great deal of information for parents, preferably in the form of ongoing dialogue before, during and after testing. This information should cover at least the following: the purposes of developmental assessment, what will happen during an assessment, the meaning of the test, the implications of the child's performance, and approaches to the child's developmental needs.

4. Involve parents as partners and peers in the process of planning and implementing a developmental assessment. Set clear but flexible guidelines. Respect and listen to parents' knowledge of their own children.

5. Strive to increase the validity of test results by gathering and incorporating information from parents, including information regarding their observations of their child at home, a comparison between the child's test performance and the child's behavior at home, their needs and concerns about their child, and ways to arrange the test situation to encourage the child's best performance.

When applying the model as an approach to developmental follow-up for babies at-risk for delay, this process would be repeated several times at spaced intervals, preferably with the same clinician paired with a family.

Modifications of the Model When Following Premature Infants

This project applied the assessment-intervention to a population of premature infants. The findings suggest that the model should accommodate at least two specific needs when used with this population for the purpose of developmental follow-up. First, developmental follow-up programs should arrange for a meeting between the family and the person who will do the assessment sometime before the assessment, for the purpose of building a relationship and providing an opportunity for the developmental specialist to get to know the family and build an understanding of their needs before the assessment. The setting and timing of this meeting are probably not critical variables; the opportunity to build the relationship before the professional makes evaluative statements about the baby is the important factor. Second, parents of these babies need information that is specific to their situation, which would include an explanation of corrected age (probably offered several times to assure understanding) and information about the development of premature infants.

Why the Model Works

The interview themes suggest that this model provided an effective tool for structuring interactions with these families for the following reasons:

- The model includes reminders about ways to establish a workable communication style. Items on the checklist target informal conversation, flexible timing, and attention to the baby as an individual. The principle concerning providing information for parents presupposes that the professional will provide open, honest, and extensive information. The principle that urges the developmental specialist to find out what understandings, expectations and needs parents bring to an assessment presupposes that the professional will set up an atmosphere of listening to parents and establish the foundation for empathy about the parents' situation.

- The model specifically plans for effective involvement of parents as team members with meaningful and valued input into the assessment process. This takes place within a continuing relationship between the same professional-parent pair.

- The model builds in specific ways to plan for the baby's best performance, with guidance from the baby's parents.

- The model proactively provides information for parents at every point of the assessment process. Since the principles encourage flexibility and sensitivity to the needs of each family, the model accommodates individual needs for specific categories of information.

Implications for Parent-Professional Communication in Early Intervention

The first four groups of final interview themes are related to one another in a way that is particularly significant for communication between parents and professionals in early intervention programs and any developmental assessment setting. These four groups of themes are:

1. Approach to Communication

|

2. The Parent-Professional Relationship

|

3. Information

|

4. Functions of Information

During the final interviews, two of the parents explained quite clearly how these four areas relate to each other. First, one mother of a 31-week premature infant explained

that, without a good relationship with a particular professional, she is unlikely to trust that professional's opinion or follow his or her recommendations. She offered an example, describing a developmental specialist who had done one developmental assessment with the baby, but who had not established a good relationship with the mother during the course of their interactions. When describing her reactions to the information and recommendations offered by this professional, the mother said, "I didn't feel like she was a support person.... I think if she had made some recommendations to me...I probably wouldn't have trusted her opinion. And I think it was because we were never able to establish a relationship. Some people you work with you are never able to establish a good working relationship. And I didn't feel comfortable talking with her. I just felt like she was a person who knew a lot and I knew nothing and at that point I really felt like I knew nothing. That was hard too. That was another barrier."

The sequence that this mother suggests is extremely important. She says that: (1) She did not feel like this professional was a support person and she did not feel comfortable talking with her. (2) They were not able to establish a good working relationship. (3) Added to this was the barrier that, at that point, she felt that as a mother she knew nothing. (4) The result was that she did not trust this professional's opinion and did not think that she would follow recommendations from her.

This sequence directly parallels the order of the first four groups of interview themes: the approach to communication, followed by the establishment of a parent-professional relationship, then the sharing of information, and finally the functions of information, which include matching developmental activities to the baby's level and making decisions about following recommendations. In the instance that this mother describes, the professional did not set up a comfortable approach to communication, which precluded developing a good working relationship with the mother. She did not have and was not provided with adequate information. Given the lack of good communication and the lack of a relationship in which the parent and professional were working together, even if this particular professional told or showed the mother certain bits of information, it would have been hard for the mother to receive it. In any case, the lack of effectively communicated information left her unprepared to follow recommendations from this professional.

Another mother, who had premature twins, presented a fascinating description of how her needs and reactions to the developmental specialist changed over time. In this case, the mother and the professional did establish a good working relationship. She explains the process in this way:

"Well I think at the beginning when you're first starting you're still nervous about your baby.... You want to feel more comfortable I think with the person that is doing the assessing and I guess maybe the quality of what is being done. And if it goes on you get to know the assessor, then it changes into what she is actually doing and how you can go about helping the whole situation.... It's like the quality of the whole testing and the whole idea of the testing becomes more important towards the end or after you feel comfortable. All that seems more important than the minor issues of the whole thing. The quality and how can I make the premature baby, you know, develop correctly. That becomes more important than all the little bitsy things."

This mother describes the same order for the process of her communication with the professional who did the assessments with her babies. (1) First, she needs to feel comfortable with the person who is doing the assessing. (2) If she comes to feel comfortable, then she can move on to "get to know" the assessor. (3) Once past this, she focusses more on what the examiner does and how she as the mother can help in the whole assessment situation. In other words, feeling comfortable about the process frees her to focus on the developmental intricacies, like just what affects the babies' developmental behavior during the assessment, and how she can help her child develop.

When reflecting on the sequence that these mothers describe in the communication process with professionals, it becomes clear how easy it is to miss some of the foundational steps in the communication process, and then never effectively get to the "functions of information." With the best of intentions, a professional may try to get a parent to carry out developmental activities matched to a baby's developmental levels and needs, or to make decisions about placement and programming. If the particular parent and professional do not have an adequate foundation of comfortable communication and a working partnership, and if the parent does not have adequate information to fully understand the recommendations, the parent may not effectively accomplish the developmental intervention. As a parent, it is a very different process to receive conclusions about a baby from a professional, as compared to working together with a professional to understand a baby and develop joint conclusions. In the first case, parents enter the process of acquiring information at the end of a four-step process, without benefit of the first three steps. In the second case, parents have a valuable foundation when it is time to integrate conclusions about their baby. Perhaps sometimes, as professionals, we are ready to discuss developmental interventions, when the parent still needs to feel like a part of the team, or to see for himself or herself what a baby's developmental needs are, before interventions will make sense within the parent's own understanding of the baby. It is very different to hear someone else's conclusions about a baby after being on the sidelines during the process of assessment, as compared to hearing a professional's conclusions after working together with the professional to build an understanding of the baby.

Table 5 provides a very brief presentation of the interview themes. When viewing this table, one can see how a

similar process would ensue for parents in relation to any of the functions of information. For example, from the context of a partnership relationship with parents, within a comfortable approach to communication, a professional can share the detailed information that would enable a parent to see that a child's development in a particular area does not represent a significant delay. How different this would be from just presenting the conclusion that there is no reason to worry about a baby's social development at this time! Similarly, within the context of a working relationship with a parent, a professional can share the detailed developmental information necessary for a parent to see for himself or herself that a child's development is delayed in a particular area.

Table 5: Parent-Professional Communication

1. Approach to Communication

- comfortable, friendly style
- listen to parents, respect judgment, answer questions
- empathy
- caring response to the baby
- time to talk, accessibility
- terminology parents understand
- open, honest information

2. The Parent-Professional Relationship

- working together as equals
- professionals' expertise = knowledge
- parents' expertise = the baby
- consistent, continuing relationship improves communication

3. Information

- how child is doing developmentally
- how to facilitate development
- what to expect of the child developmentally
- information specific to premature babies
- information about corrected age
- information that meets their needs

4. Functions of Information

- lowers anxiety
- equips for interacting with professionals
- enables to observe the baby in more detail
- equips with principles of development
- helps to see babies as individuals in relation to development
- helps match activities to developmental level and need
- enables to see babies' areas of need for themselves
- helps to understand reasons behind assessment, recommendations, conclusions
- equips to make decisions
- helps feel more comfortable with test process
- builds confidence in selves as parents

Within this four-step understanding of parent-professional communication, the "functions of information" are outcomes of effective assessment-intervention, and parents and professionals need to move through the process to reach these outcomes. When viewed from this perspective, time spent establishing a comfortable atmosphere for communication, building a relationship in which parents' knowledge of their baby is incorporated into the assessment process, and sharing detailed information with parents about the assessment process and developmental observations is time well spent. These activities equip parents to observe their babies, meet their babies' developmental needs, understand principles of development, see their babies' areas of developmental concern, and make effective decisions about intervention. With these understandings, they are also ready to interact effectively with professionals, they are prepared enough to feel comfortable with assessment, and they naturally feel more confident in themselves as parents.

Implications for Implementation of P. L. 99-457

When developing an Individual Family Service Plan with parents, early intervention professionals are clearly called to work together with parents to reach conclusions and intervention plans for babies. The message of the assessment-intervention process of communication that has been discussed here is clearly that this is a task within reach. The model of assessment-intervention offers one effective tool for approaching this task.

Chapter 5

SUGGESTIONS FOR PROFESSIONAL DEVELOPMENT

Reading and reflecting on approaches to assessment-intervention are valuable activities. This book provides one resource for this part of the journey to understanding interactions with parents and infants. A mother wisely reminded us, though, that "it is different when you are reading about a case in black and white, you have no idea who this person is, what they look like, or what they are like. Eventually you meet this person and talk to them, I think you benefit a lot more from them than just reading about it in a textbook. You can relate better to the situation." This chapter offers some suggestions for approaching the task of re-thinking assessment-intervention while observing or working with families, as well as some suggestions for group discussion of the principles and applications of assessment-intervention.

Some opening thoughts about activities for professional development related to assessment-intervention provide a context for this chapter.

First, consider the model from this project as a flexible model. As you reflect on the model, try to determine how it applies to your own setting and your own approach to parents, and how you might modify the model to better fit the contingencies of your program. Also listen carefully to the parents you work with, to figure out how to accommodate to their particular needs within the flexibility of the model.

Consider application of the model as a tool for your own journey toward understanding parents. "Understanding parents" is not a point any of us arrives at, but a process in which we each engage continuously.

Suggested Activities for Professional Development

Activities Using the Checklist for Assessment-Intervention

The Checklist for Assessment-Intervention in Appendix D will serve as a tool for staff development as well as a tool for planning and implementing assessments. Ideas for training activities using the checklist include the following:

- Use the checklist when observing someone else doing an assessment. Note which items occur, and reflect on the implications for the flow of the assessment.
- Use the checklist as a self-monitoring tool, completing it after an assessment that you do, and noticing which items you included during the course of the assessment.
- Go through the checklist during a staff meeting and adapt to your own assessment setting.

- Before an assessment, go through the checklist and note which items you think will be especially important for this particular family. Write down why you think those items are significant for this family. After the assessment, compare you perspective on the family with the notes you recorded beforehand.

- Use the checklist to develop consistent use of the principles of assessment-intervention (presented in chapter two) across staff members. After discussing the principles as a staff, have staff members observe one another, completing the checklist during the observation, and talking about the assessments afterward.

Empathy-Building Activities

An observation can accomplish different purposes depending on the focus in the mind of the observer. An observation to determine whether certain activities on a checklist occur during an assessment accomplishes one purpose. An observation directed toward imagining what it would feel like to be in the position of the parent during an assessment accomplishes a very different purpose. One activity that will sensitize professionals to the perspectives and feelings of parents is to observe with parent feelings as the focus.

Questions that might guide an observer during such an observation include the following:

- How might you feel if this was your baby?

- What do you know, or what clues can you pick up about past experiences that might affect the way this parent feels about the assessment?

- What did this parent learn about the assessment process? about the baby? How was this information conveyed?

- What messages do you think the parent got about his or her role and contribution to the assessment? How did the professional send those messages?

Adapting Other Assessment Resources

The checklists and interview guides from the project, which are in the appendices, offer ideas and structures that can be applied to other settings and needs. One valuable activity involves choosing one of these forms and adapting it to a need in a particular early intervention or developmental follow-up program.

A second activity that adapts existing assessment resources involves discussing the items on assessment instruments, with the aim of identifying the developmental demands of each task in the instrument. Through this activity, professionals become more aware of the developmental information parents will need in order to understand the significance of their child's responses to the items.

Principles of Assessment-Intervention

The principles of assessment-intervention, which are discussed in chapter two, provide a good beginning for discussion in small groups. The task in a discussion oriented to these principles is for the group members to identify specific assessment-intervention practices that apply to each principle, so that each person thinks through the practices that effectively translate the principles into action. One approach to this task involves working through the assessment structures and practices in a particular program setting, and deciding how these structures and practices relate to the principles of assessment- intervention. Another approach involves discussing the following questions:

Principle: Find out what understandings, expectations and needs a family brings to an assessment. These set the context for parents' reactions.

- What would you want to know about a parent's understanding of a developmental assessment before it occurs? What questions would you ask to find out?
- What questions would you ask to determine a parent's needs in relation to a developmental assessment (i.e., needs that an assessment could address)?

Principle: Aim to establish a caring, comfortable relationship between professional and parents, with contacts before, during and after assessments. Convey that we care about both babies and their parents.

- What behaviors on the part of a professional would tend to establish a comfortable relationship with parents?
- What behaviors would send the message that a professional cares about a baby?

Principle: Provide a great deal of information for parents, preferably in the form of ongoing dialogue before, during and after an assessment.

- What items of information do you think parents would consistently need from a developmental assessment?
- What ways of presenting information do you think would maximize parents' acquisition of information from a developmental assessment?

Principle: Treat parents as partners and peers in the process of planning and implementing a developmental assessment. Set clear but flexible guidelines. Respect and listen to parents' knowledge of their own children.

- What behaviors on the part of professionals would send the message that we consider parents as valuable partners in an assessment?

- What guidelines would you lay out for parents concerning their role during the assessment session itself?

Principle: Strive to increase the validity of test results by gathering and incorporating information from parents.

- What information from parents would increase the validity of test results?

- How would you structure interactions with parents to obtain and use this information?

Activities Concerning Assessment Reports

Assessment reports can be written with different purposes, depending on the intended audience. A report written primarily for parents will look different from a report written primarily for professionals with a background in developmental assessment. A report written with both audiences in mind will look somewhat different from one written for either one or the other. These two activities may help staff design report formats specific to the needs of a particular program.

- Collect a sampling of assessment reports. Read each one from the perspective of a parent, and try to determine how effectively it communicates developmental information.

- Experiment with report formats. Consider factors such as the order used to present the information, the terminology used, the amount of information conveyed, and the strategies used to integrate developmental information from parents.

The sample report formats in Appendix F illustrate some modifications that could results from this activity. These formats emphasize incorporating descriptions of developmental areas, to provide this information as a context for the assessment results. In addition, the report format for assessments using the Bayley Scale includes some suggestions for incorporating information from parents in the body of the report.

Suggestions for Staff Discussion

Ideas for staff discussion include the following:

- Discuss the assessment-intervention as consultation offered by a developmental specialist to parents.

The consultation terminology of Blake and Mouton (1983) may be useful during a discussion about the parallels that may

exist between a conventional consulting relationship and the relationship between a parent and a professional. Blake and Mouton present detailed descriptions of different types of consultation. For example, "theories and principles" consultation emphasizes communicating broader concepts for generalization. "Prescriptive consultation" sets forth a specific plan for the person receiving the consultation to implement, but does not emphasize the principles behind the prescription. "Acceptant consultation" emphasizes listening in a non-judgmental way to the recipient of the consultation. "Catalytic consultation" helps the person gather information and then make a decision. "Confrontational consultation" defines a crisis and authoritatively tells the people in crisis what to do. A group of professionals might discuss how these different approaches relate to the interactions between parents and professionals.

- Look at the functions of information identified in the interview themes in chapter three. For each function, discuss the relationships to communication approach between parents and professionals; the type of relationship between parents and professionals; and the information that parents would need in order to achieve the desired result.

- Discuss reactions to the assessment-intervention model. Which aspects are you eager to try? What reservations do you have?

- At first glance, it might seem that the assessment-intervention model applies more readily to parents with more educational background. An alternative perspective is that it applies more to parents with less background and less confidence in their own parenting abilities, because these parents may need more information from assessments, and time spent developing good communication and a good partnership relationship may be especially important. Discuss your reactions to these different perspectives.

Interview Ideas

Interviews provide an especially effective tool for building understanding among professionals about what the assessment process is like for parents. Interviews may be used for a program staff to evaluate the structure of assessments in a particular program, for an individual to reflect on his or her own approaches to developmental assessment, and when talking with parents after observing an assessment done by another professional. Sample interview question, based on the major groups of final interview themes from this project, include the following:

- What did you find helpful about the way the developmental specialist communicated with you? Is there anything you did not like about this?

- Did you feel like an equal partner with the person doing the assessment? Why or why not?

- What did you learn from the assessment? What questions or concerns did it leave you with?
- What will you do differently now that your child has had this assessment?
- Do you think this assessment provided a good picture of your child's abilities at this time? Why or why not?

Closing Comments

As the field of early intervention professionals prepare for the implementation phase of P. L. 99-457, numerous questions arise about how to effectively work with families whose infants and young children are at risk for developmental delays. The assessment-intervention model provides an inviting format for professional-parent teaming: a uniquely adaptable model for early interventionists, young and old. We encourage you to consider its utility and its flexibility. We welcome your comments.

References

Allen, L., Conners, E., Neysmith-Roy, J., Jacobs, S. L., & Weber, N. (1988, September). Cross-cultural issues in service delivery. Symposium presented at the third biennial conference of the International Association for Infant Mental Health, Providence, RI.

Bailey, D. B., & Simeonsson, R. J. (1984). Critical issues underlying research and intervention with families of young handicapped children. Journal of the Division for Early Childhood, 9, 38-48.

Barber, P. A., Turnbull, A. P., Behr, S. K., & Kerns, G. M. (1988). A family systems perspective on early childhood special education. In S. L. Odom & M. B. Karnes (Eds.,), Early intervention for infants and children with handicaps (pp. 179-198). Baltimore: Paul H. Brookes.

Barritt, L. S., Beekman, A. J., Bleeker, H., & Mulderij, K. (1979). Meaningful educational research: A descriptive phenomenological approach. Unpublished manuscript. University of Michigan, Department of Education, Ann Arbor.

Bayley, N. (1969). Manual for the Bayley scales of infant development. New York: Psychological Corporation.

Blumer, H. (1969). Symbolic interactionism: Perspective and method. Englewood Cliffs, NJ: Prentice Hall.

Bowlby, J. (1969). Attachment and loss. Vol. 1. Attachment. New York: Basic Books.

Bradley-Johnson, S. (1982). Infant assessment as intervention and parent education. Infant Mental Health Journal, 3, 293-297.

Brazelton, T. B. (1981). Assessment as a method for enhancing infant development. Zero to Three: Bulletin of National Center for Clinical Infant Programs, 2(1), 1-8.

Brazelton, T. B. Neonatal behavioral assessment scale (2nd ed.). Philadelphia: J. B. Lippincott, 1984.

Brown, L. K. (1975). Familial dialectics in a clinical context. Human Development, 18, 223-238.

Bustan, D. & Sagi, A. (1984). Effects of early hospital-based intervnetion on mothers and their preterm infants. Journal of Applied Developmental Psychology, 5, 305-317.

Chatoor, I., Schaefer, S., Dickson, L., & Egan, J. (1985). A developmental approach to feeding disturbances: Failure to thrive and growth disorders in infants and young children. Zero to Three: Bulletin of Natinal Center for Clinical Infant Programs, 5(3), 12-37.

Chinn, P. C., Winn, J., & Walters, R. (1978). Two-way talking with parents of special children: A program of positive communication. St. Louis: Mosby.

Eisner, E. (1983). Anastasia might still be alive, but the monarchy is dead. Educational Researcher, 12, 23-24.

Field, T., Dempsey, J., & Shuman, H. (1981). Developmental follow-up of pre- and postterm infants. In S. Friedman & M. Sigman (Eds.), Preterm birth and psychological development (pp. 299-312). New York: Academic Press.

Foster, M. A., & Berger, M. (1979). Structural family therapy: Applications in programs for preschool handicapped children. Journal of the Division for Early Childhood, 1, 52-58.

Fox, N. A., & Feiring, C. (1985). High-risk birth: Effects of illness and prematurity on the mother-infant interactions and the mother's social support system. In S. Harel & N. J. Anastasiow (Eds.), The at-risk infant (pp. 19-28). Baltimore: Paul H. Brookes.

Fox, N. A., & Lewis, M. (1982). Prematurity, illness, and experience as factors in preterm development. Journal of the Division for Early Childhood, 6, 60-72.

Furuno, S., O'Reilly, K., & Ahern, F. (1985). Transdisciplinary teamwork with parents of premature infants. In S. Harel & N. J. Anastasiow (Eds.), The at-risk infant (pp. 51-64). Baltimore: Paul H. Brookes.

Hanson, J. L. P. (1984). Effects of developmental evaluations on parents of infants and young children. Dissertation Abstracts International, 44, 490A. (University Microfilm Number 800-521-3042)

Heinicke, C. M., Beckwith, L., & Thompson, A. (1988). Early intervention in the family system: A framework and review. Infant Mental Health Journal, 9(2), 111-141.

Hubatch, L. M., Johnson, C. J., Kistler, D. J., Burns, W. J., & Moneka, W. (1985). Early language abilities of high-risk infants. Journal of Speech and Hearing Disorders, 50, 195-207.

Hunt, J. V. (1981). Predicting intellectual disorders in childhood for preterm infants with birthweights below 1501 gm. In S. Friedman & M. Sigman (Eds.), Preterm birth and psychological development (pp. 329-351). New York: Academic Press.

Klaus, M. H., & Kennell, J. H. (1981). Maternal-infant bonding (2nd ed.). St. Louis: C. V. Mosby.

Klein, P., & Feuerstein, R. (1985). Environmental variables and cognitive development: Identification of the potent factors in adult-child interaction. In S. Harel & N. J. Anastasiow (Eds.), The at-risk infant (pp. 369-378). Baltimore: Paul H. Brookes.

Klein, N., Hack, M., Gallagher, J., & Fanaroff, A. A. (1985). Preschool performance of children with normal intelligence who were very low-birth-weight infants. Pediatrics, 75, 532-537.

Lincoln, Y. S. (1988, July). Naturalistic inquiry. Paper presented at the Office of Special Education Programs (OSEP) Research Project Directors' Conference, Washington, DC.

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Beverly Hills: Sage.

Mahler, M. S., Pine, F., & Bergman, A. (1975). The psychological birth of the human infant. New York: Basic Books.

McGonigel, M. J., & Garland, C. W. (1988). The individualized family service plan and the early intervention team: Team and family issues and recommended practices. Infants and Young Children, 1(1), 10-21.

Meisels, S. J., & Anastasiow, N. J. (1982). The risks of prediction: Relationships between etiology, handicapping conditions, and developmental outcomes. In S. G. Moore & C. R. Cooper (Eds.), The young child: Reviews of research (Vol. 3, pp. 259-280). Washington, DC: National Association for the Education of Young Children.

Meisels, S. J., Plunkett, J. W., Pasick, P. L., Stiefel, G. S., & Roloff, D. W. (1985). Subdividing the risks of prematurity: Cognitive development of preterm infants with chronic and severre respiratory illness. Unpublished manuscript, The University of Michigan, Ann Arbor.

Moran, M. A. (1985). Families in early intervention: Effects of program variables. Zero to Three: Bulletin of National Center for Clinical Infant Programs, 5(5), 11-14.

Neyhus, A. S., & Neyhus, M. (1979). Relationship of parents and teachers in the identification of children with suspected learning disabilities. Journal of Learning Disabilities, 12, 379-383.

Nugent, J. K. (1985). Using the NBAS with infants and their families: Guidelines for intervention. White Plains, NY: March of Dimes.

Parmelee, A. H., & Cohen, S. E. (1985). Neonatal follow-up services for infants at risk. In S. Harel & N. J. Anastasiow (Eds.), The at-risk infant (pp. 269-273). Baltimore: Paul H. Brookes.

Rogers, S. A. (1978). A child's evaluation: It's a family affair. In S. L. Brown & M. S. Moersch (Eds.), Parents on the team (pp. 69-76). Ann Arbor: University of Michigan Press.

Satir, V. (1967). Conjoint family therapy. Palo Alto, CA: Science and Behavior Books.

Seibert, J. M., & Hogan, A. E. (1982). A model for assessing social and object skills andplanning intervention. In D. P. McClowry, A. M. Guilford, & S. O. Richardson (Eds.), Infant communication: Development, assessment, and intervention (pp. 21-54). New York: Grune and Stratton.

Sexton, D., Hall, J., & Thomas, P. J. (1984). Multisource assessment of young handicapped children: A comparison. Exceptional Children, 50, 556-558.

Sexton, D., Miller, J. H., & Murdock, J. Y. (1984). Correlates of parental-professional congruency scores in the assessment of young handicapped children. Journal of the Division for Early Childhood, 8, 99-106.

Siegel, L. S. (1985). Biological and environmental variables as predictors of intellectual functioning at 6 years of age. In S. Harel & N. J. Anastasiow (Eds.), The at-risk infant (pp. 65-74). Baltimore: Paul H. Brookes.

Shonkoff, J. P., Hauser-Cram, P., Krauss, M. W., & Upshur, C. C. (1988). A community of commitment: Parents, programs, and the early intervention collaborative study. Zero to Three: Bulletin of National Center for Clinical Infant Programs, 8(5), 1-6.

Spradley, J. P., & McCurdy, D. W. (1972). The cultural experience: Ethnography in complex society. Chicago: Science Research Associates.

Stainbeck, S. & Stainbeck, W. (1984). Broadening the research perspective in special education. Exceptional Children, 50(5), 400-409.

Stainbeck, S., & Stainbeck, W. (1988). Understanding and conducting qualitative research. Reston, VA: Council for Exceptional Children.

Stone, N. W. (1979). Attachment in handicapped infant-family systems. Journal of the Division for Early Childhood, 1, 28-32.

Tiffany, D., Cohen, J. I., Robinson, A. M., & Ogburn, K. C. (Eds.). (1975). Helping families to change. New York: Jason Aronson.

Vincent, L. (1985). Promoting parent professional relationships. Presentation for the Association of the State Directors of Special Education, Minneapolis, Minnesota.

BEST COPY AVAILABLE

Appendix A

A Parent-Sensitive Model for Developmental Evaluations

(c) 1984, Janice Lynn Peterson Hanson

Meeting parents' needs during a developmental evaluation involves pursuing at least three aims: (a) to establish a comfortable relationship between the evaluator and the parents and child, setting the evaluation in the context of a continuing relationship with contacts between evaluator and family before, during, and after the test session; (b) to convey clear and specific information to parents regarding the purpose of developmental evaluation, what will happen during an evaluation, what their roles as parents include during an evaluation, the meaning of the test, the implications of the child's performance, and approaches to the child's developmental needs; and (c) to gather and incorporate information from parents regarding their observations of their child at home, a comparison between the child's test performance and the child's behavior at home, their needs and concerns about their child, and ways to arrange the test situation to encourage the child's best performance.

The following checklists provide considerations to help an evaluator meet these aims. The checklists appear in Effects of Developmental Evaluations on Parents of Infants and Young Children, a dissertation submitted for the Ph.D. degree in Education at the University of Michigan and abstracted in Dissertation Abstracts International.

Talking with Parents Before a Developmental Evaluation

Point to consider regarding parents' perceptions of their child's developmental needs:

___parents' current perceptions of the child's abilities and needs
___parents' understanding of the implications of the child's developmental differences
___parents' background knowledge about child development (e.g., does this parent have training in teaching, nursing; has this parent read books about child development)
___parents' time available to spend with the child (e.g., a mother may have had more opportunity to observe a child's skills at home than a father
___other children available to parents for comparison of development
___child's size (i.e., parent may unconsciously expect less of a small child)
___child's age (i.e., parents of older children have had more opportunity to become aware of the degree of their child's delay from their own observations)
___information parents have received from other sources about their child's developmental needs or about the evaluation process.

Points to discuss with parents when arranging an evaluation:

___will the child perform better at a certain time of day?
___will the place affect the child's performance? (e.g., would a prior visit to the evaluation room help the child feel more comfortable; is this child fairly comfortable in strange places; would the child perform better if the evaluation took place at home)
___is it possible to arrange a visit (e.g., to an early intervention program) for the child to meet the evaluator and see the evaluation room?
___the parents may want to bring a familiar toy for the child
___make it clear that both parent are welcome to attend the evaluation. Would an appointment at a certain time make this possible?
___suggest that the parents think about their concerns and questions ahead of time, perhaps writing them down and bringing a list to the evaluation

Enhancing the Relationship between Evaluator and Family

___arrange for someone to greet the family as soon as they arrive
___have chairs ready for parents in the evaluation room
___engage in some casual conversation with parents before or after testing
___smile
___respond receptively to parents' comments and questions
___share information with parents openly and honestly
___adopt a comfortable attitude as the evaluator
___know test materials and administration thoroughly
___limit the number of evaluators to one or at most two
___make positive comments bout the parents' interactions with the child
___mention the child's outfit or smile
___take time beyond that needed for testing to hold, play with, and talk to the child
___use a gentle voice and manner with the child
___cue into the needs of the child (e.g., whether the child is hot, sleepy, hungry, or wet) and allow time for parents to make the child more comfortable
___give the child time to respond to test items
___give the child several opportunities to respond to an item if necessary

Information Parents Desire from Developmental Evaluators

Topics of information:

___the child's developmental age levels
___explanation of the meaning of developmental age levels (i.e., how they are derived, who is in the comparison group)
___child's developmental needs--specific areas where the child needs help (relate these to observation of performance during the test)
___suggestions about what to do if the child has problems referrals to programs, therapy, or further evaluation; specific ideas of ways to work with the child at home
___specific information about how to contact programs (phone numbers, addresses, names of people to call)

(phone numbers, addresses, names of people to call)
___what to expect from future intervention programs
___realistic developmental expectations on a short term basis
___referral to parents of similar children (e.g., children with the same chromosomal difference as their own)
___meaning of test items--what an evaluator looks for in the child's responses
___explanations of what the child does and does not do (relate these to responses to test items)
___expected performance for the child's age
___what the child does well
___explanation of the test--areas covered, name of test, what the test can tell
___comments that foster hope or reassurance about the child

Points that foster hope for a child with special needs:

___signs of developmental progress in the child
___comments about something the child does well
___reassurance that even with special needs the child will make progress
___information about available services, programs, or medical interventions
___reference to other similar children that have improved or done well
___observations about positive characteristics in the child (e.g., good health, good hearing, pleasing temperament, attractive appearance)

Helpful characteristics for presentation of information:

___present information in understandable terms
___offer information beyond that parents specifically request
___offer parents a copy of the written report
___do not assume parents know much about the evaluation process
___provide demonstrations of terms and recommended activities
___share information openly and honestly
___provide information needed for parent participation in individual education plan meetings if applicable (e.g., provide information in the form of the child's strengths and weaknesses)

<u>Suggestions for Parent Involvement During Developmental Evaluations</u>

___set guidelines for parent participation at the beginning of the test session
___mention specifically that parents may ask questions
___invite parents' suggestions about ways to encourage the child to respond; follow the suggestions
___invite parents' observations of their child's abilities at home
___ask parents to describe behaviors not tapped by the test
___incorporate parens' comments about their children at home into discussions bout test results and into the

written test report
___ask parents for a comparison of their child's test performance with what they have seen at home
___invite parents' suggestions for program goals before writing the goals
___arrange for both parents to attend the evaluation if possible
___ask the parent to hold a baby during testing
___if a child refuses to try a test item, ask a parent to attempt to get the child to respond
___have parent feed, change, or comfort a child as necessary
___to avoid a parent erroneously reporting that a child can perform a skill, explain exactly what the skill involves when asking a parent if the child can perform it at home
___when focussing on a particular ability, try to activity with the child first. If the child does not accomplish it, then ask the parent if the child has done it at home
___when other professionals are in the room, direct comments to parents as well as the professionals
___confine interactions with parent during testing to the examiner; i.e., allow parents to observe testing without answering questions from another professional at the same time.

Suggestions for Follow-up Interactions with Parents

___offer parents the opportunity to call back with questions that arise when they arrive home or when they receive a copy of the written test report
___deliver further results and reports promptly
___promptly make necessary referrals to programs or further evaluations
___call parents with an answer to one of their questions, a reference concerning an issue discussed during the evaluation, names or phone numbers of services they can contact, or other information not available at the time of the evaluation
___supply parents with a copy of the written evaluation report
___supply recommendations for home activities to encourage the child's developmental progress or referral to a program that can recommends such activities
___incorporate information from parents into the written report. Parents' comments about the comparison between their child's test performance and the abilities they have observed at home fit nicely into statements about the validity of the child's test performance. Parents' descriptions of a child's abilities can supplement test observations.

Appendix B

Pre-Assessment Interview Guide

For each pre-assessment interview, review the following information, which covers the first component of the assessment-as-intervention model. Then discuss the coming assessment with the parents by asking the parents to respond to the checklist of options at the end of this guide. In addition, make notations as indicated.

Most of the points on the following pages can be covered on the phone before the assessment, when you call to schedule. Some points, if you miss them on the phone, you can cover when you arrive for the assessment. A second phone call before the assessment is also okay.

Opening thoughts

Meeting parents' needs during a developmental evaluation involves pursuing at least three aims: (a) to establish a comfortable relationship between the evaluator and the parents and child, setting the evaluation in the context of a continuing relationship with contacts between evaluator and family before, during, and after the test session; (b) to convey clear and specific information to parents regarding the purposes of developmental evaluation, what will happen during an evaluation, what their roles as parents include during an evaluation, the meaning of the test, the implications of the child's performance, and approaches to the child's developmental needs; and (c) to gather and incorporate information from parents regarding their observations of their child at home, a comparison between the child's test performance and the child's behavior at home, their needs and concerns about their child, and ways to arrange the test situation to encourage the child's best performance.

Talking with Parents Before a Developmental Evaluation

Points to consider regarding parents' perceptions of their child's developmental needs:

(Do not try to elicit this information specifically. Just listen to parents' comments and keep notes.)

___parents' current perceptions of the child's abilities and needs

___parents' understanding of the implications of the child's developmental differences

___parents' background knowledge about child development (e.g., does this parent have training in teaching, nursing; has this parent read books about child development)

___parents' time available to spend with child (e.g., a mother may have had more opportunity to observe a child's skills at home than a father)

___other children available to parents for comparison of development

___child's size (i.e., parents may unconsciously expect less of a small child)

___child's age (i.e., parents of older children have had more opportunity to observe their child's development. Does parent correct for gestational age?)

___information parents have received from other sources about their child's developmental needs or about the evaluation process (e.g., information given to them by referring physicians)

Points to discuss with parents when arranging an evaluation:

(Check off each point as you discuss it with parents. Also jot notes about their responses.)

Principle #1: Plan with parents how to enhance the child's performance

___will the child perform better at a certain time of day?

___do you prefer that the evaluation be done in your home or at the clinic? Do you think that the place will affect your child's performance?

___if coming to the clinic for the evaluation, suggest that the parents may want to bring a familiar toy for the child to help him or her feel more comfortable

___can the parent think of anything else that might help their child perform at his or her best?

Principle #2: Respond to parents' preferences and needs

___make it clear that both parents are welcome to attend the evaluation. Would an appointment at a certain time of day make this possible?

___if both parents cannot or do not wish to attend, is there someone else the parent would like to be there? Make it clear that this is only important if it would make the parent more comfortable about the evaluation.

Principle #3: Discuss the parents' questions and concerns

___ask the parents whether any other questions or concerns about the evaluation or about their child's development come to mind at this time

___suggest that the parents think about their concerns and questions ahead of time, perhaps writing them down and bringing a list to the evaluation

Principle #4: Give parents information about what the assessment will involve

___give an explanation of what the assessment is about, including:

a) a statement that it will provide information about the child's development
b) a statement that it is not predictive
c) examples of items

d) an estimate of the amount of time needed
e) a statement that you will tell the parent if you see anything that causes concern

___mention the need for a table if the assessment will take place at home

Checklist of Assessment Options

1. Is time of day important for the assessment?
   Y/N
   If yes, what time do you prefer?

2. Is location of the assessment important for you and your child (home or clinic)?
   Y/N
   If yes, which do you prefer?

3. Would you like both parents to attend the assessment?
   Y/N
   If yes, how can we facilitate this?

4. Do you want a written report after the assessment?

5. Do you have a preference for the way the evaluator presents any developmental suggestions?
   Y/N
   If yes, do you prefer demonstrations with explanations, opportunities to perform the suggestions with your child while the evaluator comments, written suggestions, or other?

6. What items of information do you want from this evaluation?
   ___your child's developmental age levels
   ___explanations about the meaning of developmental ages (i.e., how we get them)
   ___specific areas where your child might need assistance
   ___referrals to other services
   ___suggestions about how to handle or plan with your child to help his or her development
   ___developmental steps you can expect from your child soon
   ___referral to parents of children with a similar medical history
   ___the meaning of test items; what an evaluator looks for in your child's response
   ___expected performance for your child's age
   ___what your child does well
   ___explanations about the test itself; its name, what it tests, what it can and cannot tell us
   ___signs of developmental progress in your child
   ___other

7. Do you have any other ideas about how you would like the assessment to go? (please list below)

Appendix C

Planning Form for Assessment/Intervention

Before each assessment/intervention session, the researcher will review the following guidelines. On the basis of the pre-assessment interview, the researcher will mark the items in the guidelines that seem most important for this particular family. At the end of the guidelines, the researcher will write a list in response to the questions, "What features or characteristics of this family have led you to mark the above items in these planning guidelines.

Enhancing the Relationship between Evaluator and Family

(Note occurrence or lack of occurrence of each item. Keep relevant notes.)

___if evaluation occurs at the clinic, arrange for someone to greet the family as soon as they arrive

___if evaluation occurs at the clinic, have chairs ready for parents in the evaluation room

___engage in some casual conversation with parents before or after testing

___respond receptively to parents' comments and questions

___share information with parents openly and honestly

___limit the number of evaluators to one or at most two

___make positive comments about the parents' interactions with the child

___mention something about the child's appearance (e.g., the child's outfit or smile)

___take time beyond that needed for testing to hold, play with, and talk to the child

___use a gentle voice and manner with the child

___cue into the needs of the child (e.g., whether the child is hot, sleepy, hungry, or wet) and allow time for parents to make the child more comfortable

___pace the test items according to the child's needs (e.g., give the child adequate time to respond to test items, move quickly for a child with a short attention span)

___give the child several opportunities to respond to an item if necessary

___have test materials organized for administration

Information Parents Desire from Developmental Evaluators

Topics of information for all parents:

(Note whether or not each item of information was shared with parents. Keep relevant notes.)

___the child's developmental age levels

___explanation of the meaning of developmental age levels (i.e., how they are derived, who is in the comparison group

___meaning of test items--what an evaluator looks for in the child's responses

___explanation of what the child does and does not do (relate these to responses to test items)

___what the child does well

___explanation of the test--areas covered, name of test, what the test can tell

___specific ideas of ways to work with the child

Other items of information parents may want: (Keep relevant notes.)

___expected performance for the child's age

___child's developmental needs--specific areas where the child needs help (relate these to observations of performance during the test)

___suggestions about what to do if the child has problems--referrals to programs, therapy, or further evaluation; specific ideas of ways to work with the child at home

___specific information about how to contact programs (phone numbers, addresses, names of people to call)

___what to expect from future interventions programs

___realistic developmental expectations on a short-term basis

___referral to parents of children with similar medical histories

___comments that offer reassurance about the child's development

Helpful characteristics for presentation of information: (Keep relevant notes)

___present information in understandable terms

___offer information beyond that parents specifically request

___offer parents a copy of the written report

___do not assume parents know much about the evaluation process

___provide demonstrations of terms and recommended activities

___share information openly and honestly

___provide information needed for parent participation in individual education plan meetings if applicable (e.g., provide information in the form of the child's strengths and weaknesses)

Suggestions for Parent Involvement During Developmental Evaluations

(Note occurrence or lack of occurrence for each item. Keep relevant notes.)

___ask at the beginning of the test session whether parents have anything in particular they would like you to observe while testing

___set guidelines for parent participation at the beginning of the test session

___mention specifically that parents may ask questions

___invite parens' suggestions about ways to encourage the child to respond; follow the suggestions

___invite parents' observations of their child's abilities at home

___ask parents to describe behaviors not tapped by the test

___incorporate parents' comments about their children at home into discussions bout test results and into the written test report

___ask parents for a comparison of their child's test performance with what they have seen at home

___arrange for both parents to attend the evaluation if possible and parents desire

___ask the parent to hold a baby during testing

___if a child refuses to try a test item, ask a parent to attempt to get the child to respond

___have parents feed, change, or comfort a child as necessary

___to avoid a parent erroneously reporting that a child can perform a skill, explain exactly what the skill involves when asking a parent if the child can perform it at home

___when focussing on a particular ability, try the activity with the child first. If the child does not accomplish it, <u>then</u> ask the parent if the child has done it at home

___when other professionals are in the room, direct comments to parents as well as the professionals

___confine interactions with parents during testing to the examiner; i.e., allow parents to observe testing without answering questions from another professionals at the same time

Suggestions for Follow-up Interactions with Parents

(Keep relevant notes.)

___offer parents the opportunity to call back with questions that arise when they arrive home or when they receive a copy of the written test report

___deliver further results and reports promptly (record dates)

___promptly make necessary referrals to programs or further evaluations

___if applicable, call parents with an answer to one of their questions, a reference concerning an issue discussed during the evaluation, names or phone numbers of services they can contact, or other information not available at the time of the evaluation

___supply parents with a copy of the written evaluation report

___supply recommendations for activities to encourage the child's developmental progress

___incorporate information from parents into the written report.

Parents' comments about the comparison between their child's test performance and the abilities they have observed at home fit nicely into statements about the validity of the child's test performance. Parents' descriptions of a child's abilities can supplement test observations.

Appendix D

THE GEORGE WASHINGTON UNIVERSITY
DEPARTMENT OF TEACHER PREPARATION AND SPECIAL EDUCATION

Assessment as Intervention:
Discerning the Needs of High-Risk Infants and Their Families
Janice L. Hanson, Ph.D., Project Director

Checklist for Assessment/Intervention

(c) 1988

Throughout

___respond receptively to parents' comments and questions
___share information with parens openly and honestly
___make positive comments about the parents' interactions with the child
___mention something about the child's appearance (e.g., the child's outfit or smile)
___take time beyond that needed for testing to hold, play with, and talk to the child
___use a gentle voice and manner with the child
___cue into the needs of the child (e.g., whether the child is hot, sleepy, hungry, or wet) and allow time for parents to make the child more comfortable
___invite parents' suggestions bout ways to encourage the child to respond; follow the suggestions
___invite parents' observations of their child's abilities at home
___ask parents to describe behaviors not tapped by the test
___have parents feed, change, or comfort a child as necessary
___to avoid a parent erroneously reporting that a child can perform a skill, explain exactly what the skill involves when asking a parent if the child can perform it at home
___when other professionals are in the room, direct comments to parents as well as the professionals

Before the Test

___engage in some casual conversation with parents
___limit the number of evaluators to one or at most two
___have test materials organized for administration
___explain the test--areas covered, name of test, what the test can tell, limitations of the test as used (may be done after test)
___mention at the beginning that you will present items that you do not expect the child to accomplish. Don't wait until the child begins to fail!
___ask at the beginning of the test session whether parents have anything in particular they would like you to observe
___set guidelines for parent participation
___mention specifically that parents may ask questions
___ask parents to watch for whether their child's test performance compares to the child's typical behavior
___arrange for both parent to attend the evaluation if desired

During the Test

___pace the test items according to the child's needs
___give the child several opportunities to respond to an item if necessary
___explain meaning of test items--what an evaluator looks for in the child's responses
___explain what the child does and does not do (relate these responses to test items). Note how this relates to developmental progressions in sequences of skill acquisition.
___comment on what the child does well
___ask the parent to hold a baby during testing
___if a child refuses to try a test item, ask a parent to attempt to get the child to respond
___when focussing on a particular ability, try the activity with the child first. If the child does not accomplish it, then ask the parent if the child has done it at home
___confine interactions with parents during testing to the examiner; i.e., allow parent to observe testing without answering questions from another professional at the same time

After the Test

___give the child's developmental age levels
___explain the meaning of developmental age levels (i.e., how they are derived, who is in the comparison group)
___give specific ideas of ways to work with the child at home
___incorporate parents' comments about their children at home into discussions about test results and into the written test report
___ask parents for a comparison of their child's test performance with what they have seen at home
___explain what steps in development come next

Appendix E

Pre-Assessment Planning

Before an assessment session, cover at least the following:

--time of day for the assessment; place for the assessment; child's reactions to new situations; anything the parent thinks will optimize the child's responses

--who will attend the assessment

--information parents have received abut the assessment

--what to expect from the test session (with concrete examples)

--information about what an assessment can and cannot accomplish

--parents' current perceptions of the child's needs and abilities

--parents' concerns and questions

--a reminder to bring other questions and concerns to the assessment session

--listen for other family factor that might be relevant, as they come up in the conversation

Appendix F

BRAZELTON NEONATAL BEHAVIORAL ASSESSMENT SCALE ASSESSMENT REPORT FORMAT

Child's name:
Child's birthdate:
Gestational age at birth:
EDC (baby's due date):
Date of assessment:
Child's correct age:
Medical record number:

BACKGROUND INFORMATION

RESULTS OF ASSESSMENT

Habituation means the baby's ability to reduce his or her reactions to repeated presentations of a light, a sound, or a touch while sleeping.

Orientation means the ability to respond to sights and sounds when awake and alert.

Motor items on the Brazelton look at the baby's ability to move, the quality of the baby's movement, and the baby's ability to inhibit unnecessary movements.

Range of state refers to the baby's levels of arousal during the assessment--from deep sleep, light sleep, and drowsiness to alertness, an active awake state, and crying.

Regulation of state refers to the baby's ability to move back and forth between the different states of arousal.

Autonomic stability means the ability of the baby's autonomic nervous system (i.e., the system that controls basic functions like breathing, heart rate, and temperature control) to adjust to stress or stimulation in the environment.

Reflexes are elicited, automatic responses--specific neurological reactions to specific stimuli.

SUMMARY

RECOMMENDATIONS

Janice L. Hanson, Ph.D.
Project Director
Special Education
office: (202) 994-6170

BAYLEY SCALES OF INFANT DEVELOPMENT ASSESSMENT REPORT FORMAT

Child's name:
Child's birthdate:
Gestational age at birth:
Date of assessment:
Child's chronological age:
Child's corrected age:

Medical record number:

INSTRUMENTS USED

Bayley Scales of Infant Development: Mental Scale, Motor Scale, and Infant Behavior Record; Parent Interview and Clinical Observations

BACKGROUND INFORMATION AND BEHAVIORAL OBSERVATIONS

(Include test setting, child's behavior, and a statement about whether this assessment seems to provide an accurate picture of the child's abilities at this time. When considering whether this assessment seems representative of the child's abilities, include comments about, for example, the parents' reports of the child's abilities, the child's mood during the assessment, the parents' description of the general mood of the child and a comparison to the mood during the assessment, positioning of the child during the assessment, possible distractions, and any other information that may have affected the outcome of the assessment.)

RESULTS OF ASSESSMENT

(Include age equivalents in relation to corrected age, range of items passed, and discussion of developmental areas, including strengths and weaknesses.)

Cognitive development means the child's ability to solve problems and to explore and learn about the world with his or her eyes, ears, and hands.

Fine motor development involves the child's ability to use and coordinate small muscles, such as those needed to use his or her hands.

Gross motor development involves using and coordinating large muscles, as well as the ability to hold one's body upright.

Language development means the child's ability to communicate with sound, facial expressions, or gestures, as well as the child's response to sounds and emerging recognition and understanding of words, facial expressions, and gestures.

Social and behavioral development include the child's reactions to and interactions with other people, and the child's awareness of himself or herself. These areas also involve the child's temperament or style of interaction with the world.

IMPRESSIONS

RECOMMENDATIONS

Janice L. Hanson, Ph.D.
Project Director
office: (202) 994-6170

ALTERNATE DESCRIPTIONS OF DEVELOPMENTAL AREAS

These were written for 9 month developmental reports.

Cognitive skills at this age means the ability to connect an action with a desired result as well as remember familiar persons, toys or objects even when they leave the baby's sight.

Fine motor skills are the ability to use one's hands to explore and pick up small objects as well as the ability to secure an object with one hand while manipulating it with the other.

Gross motor skills means using the larger muscles for balance, early locomotion, and early transitions from one position to another.

Language skills are the early babbling sounds of a baby which later become the first real words, as well as the baby's ability to begin to recognize familiar names of persons or objects and associate familiar actions words with their action.

Social skills are the baby's ability to respond to familiar songs or lap games or to imitate simple motor movements of an adult.

Appendix G

Consent for Investigational Study

Title of Research:
Discerning the Needs of High-Risk Infants and Their Families

Description:
The purpose of this study is to follow babies who have been in the neonatal intensive care unit, and to develop an approach to developmental evaluation that will meet the needs of parents for developmental information and support concerning these babies. Developmental evaluation is when a developmental specialist watches a baby play, move, and do other skills and compares that baby's abilities to the abilities expected of babies the same age. In order to understand how to better meet parents' needs when their babies receive developmental evaluations, the developmental specialists doing this study plan to:
(1) meet with parents while their baby is still in the hospital,
(2) do an assessment to get acquainted with the baby at 40 weeks gestational age (the time the baby was due to be born),
(3) do a developmental evaluation with the baby at 3, 6, 9 and 12 months of age (corrected age),
(4) interview the parens before each developmental evaluation to find out what they want from the evaluation, and again after each developmental evaluation,
(5) ask parents at the end of the project to share any other suggestions they have about developmental evaluations.

These developmental evaluations and interviews would be in addition to the physicians' and physical therapist's services available through the follow-up clinic of the Division of Newborn Services at the ... Medical Center. If a parent of a baby in the neonatal intensive care unit does not want to participate in this study and the physician recommends clinic follow-up for the baby, the baby will still be followed by the regular follow-up clinic, and may receive developmental evaluations as well as physicians' and physical therapist's services when attending the clinic.

There are no expected risks or negative side effects for the babies or parents that will participate in this study. The potential benefits include:
(1) more time and more detailed developmental information available from the developmental specialist for the parents and baby,
(2) the opportunity to have the developmental specialist come to the family's home for developmental assessments and interviews, if the parents desire,
(3) the opportunity to meet with the same developmental specialist several times, and the opportunity to ask questions of this specialist during the various meetings,
(4) the opportunity for parents to affect the way their baby's developmental evaluations are done, so that the evaluations meet the needs of the parents and their baby in the best way possible, and
(5) the opportunity to schedule the developmental evaluations before the regular clinic visits, so the

information from the evaluations will be available to the physicians and physical therapist at the time of the clinic visits.

The parents' responsibility in this project is to agree to meet with the developmental specialist for the developmental evaluations and the interviews. The evaluations will generally take about 90 minutes, although the developmental specialist will be available to discuss the parents' questions for a longer time if desired. The time needed for the interviews will vary with the number of thoughts that the parents want to share. The families will not have to pay for any expenses of the research (although they will be billed for other services provided through the follow-up clinic). If the parents choose to withdraw from the study, they may obtain developmental follow-up through the regular follow-up clinic.

This study will include a total of approximately 25-30 families.

My participation in the study will be kept confidential and only those persons who are conducting the study, or who by law have the authority to have access to the information, or who are sponsoring the project will be given this information.

My participation in this study is entirely voluntary, and I may decline to take part in it or I may withdraw at any time without prejudice to my medical care.

If I have further questions concerning the research, I may contact: ...

If I have any questions concerning my rights as a research subject, I may contact the Office of Human Subjects Research ... (followed by a statement regarding compensation for adverse physical reactions, as required by the medical center)

Appendix H

Post-assessment Interview Guidelines

The post-assessment interview is conducted in person, within 2 weeks of the assessment-intervention (record date)

Purposes

1. to have parent(s) comment on the assessment-as-intervention experience.

2. to give parent(s) a written summary of the assessment results.

3. to discuss assessment results and developmental suggestions in detail with the parent(s).

Method

1. On the way to the interview, focus your thoughts on this family, your musings about their responses to the assessment, and the coming interviews.

2. Give parent(s) written summary of results at the beginning of the session. Discuss results and recommendations. Answer any questions the parent(s) have about the assessment results and recommendations.

3. Introduce the next portion of the visit by explaining that our purpose is to find out what they as parents did and did not like about the developmental assessment.

4. Go over "Checklist of Assessment Options," asking parent(s) if they would now choose any differently for any of the options. Record current choice and any pertinent comments in writing (in list form). Tape record conversation.

5. Ask the parent(s) these 2 questions:

--(a) Are there any other aspects of an assessment/intervention that you would like to help plan so that it will best meet the needs of you and your baby? (b) Is there anything you would like to change about the assessment/intervention you just experienced, so that it would better meet the needs of you and your baby?

--What features did you find especially helpful about the assessment session?

For each question, write a list of the parents' suggestions. Take notes in the form of a list of responses for each question during the interview, so that you can use the lists for member checking at the end of the interview. Also tape record the conversation for later use.

6. Do some "member checking." Show the parent(s) your lists as you go and ask them if you have interpreted their comments correctly. Tape record this portion also.

7. Review for the parents the next steps of the project. Set the stage for subsequent interviews by mentioning that

these are the kinds of questions we will be asking, so the parents can keep thoughts about these issues in mind for the next interviews. Re-iterate your availability by phone in the interim.

8. After the interview, listen to the tape and refine the lists of parents' responses to the questions.

9. Be sure to keep a log of <u>each contact with the family</u>. Jot down your thoughts about format for developmental follow-up programs. E.g., if you find yourself calling each family at a particular touch point in addition to those specified in the study, make a note of that fact and your thoughts about why. These notes may form the basis for some questions to ask in later interviews.

Also keep notes on your thoughts about the best ages for developmental assessments (in your journal).

Also make journal entries concerning your thoughts after the interview.

Note: These questions can be re-phrased so that they are open-ended rather than yes/no questions, but then do as-you-go-member checking to see if you are interpreting the parents' responses correctly.

<u>Checklist of Assessment Options</u>

1. Is time of day important for the assessment?
   Y/N
   If yes, what time do you prefer?

2. Is location of the assessment important for you and your child (home or clinic)?
   Y/N
   If yes, which do you prefer?

3. Would you like both parents to attend the assessment?
   Y/N
   If yes, how can we facilitate this?

4. Do you want a written report after the assessment?

5. Do you have a preference for the way the evaluator presents any developmental suggestions?
   Y/N
   If yes, do you prefer demonstrations with explanations, opportunities to perform the suggestions with your child while the evaluator comments, written suggestions, or other?

6. What items of information do you want from this evaluation?
   ___your child's developmental age levels
   ___explanations about the meaning of developmental ages (i.e., how we get them)
   ___specific areas where your child might need assistance
   ___referrals to other services
   ___suggestions about how to handle or plan with your child to help his or her development

___developmental steps you can expect from your child soon
___referral to parents of children with a similar medical history
___the meaning of test items; what an evaluator looks for in your child's response
___expected performance for your child's age
___what your child does well
___explanations about the test itself; its name, what it tests, what it can and cannot tell us
___signs of developmental progress in your child
___other

7. Do you have any other ideas about how you would like the assessment to go? (please list below)

Appendix I

PROCEDURES FOR ADMINISTERING PARENT INTERVIEWS FOR NINE AND TWELVE MONTH ASSESSMENTS

First, administer Bayley assessment and discuss results with parents.

Second, explain that what the research is about is learning from parents how professionals should interact with parents at a difficult time in their lives, in order to help them best. Explain that in order to do this we have to know what matters to parents and then we have to know what behaviors will communicate to parents the things that matter to them, so that we can train other people to do them. After you have given parents this introduction, ask them, "Is there anything that you have discovered that is important for professionals to do when they interact with you and your baby?"

Third, ask the questions on the first page and keep on asking questions to elicit as much information as possible. Remember that this information is the most valuable because it is the most spontaneous. Then ask again if they have anything to add.

Fourth, explain to the parent that we have come up with some principles that have guided our interactions with parents, and that we though might be important to them. Ask them to read the principles and see if they could number the three that are important to them, or if there is one that is very important to them that we have left out. Then, for each principle that they have numbered, ask them what behaviors communicate that principle to them. That is, how do they know when they are getting what they want and when they are not? For each principle, after they have come up with their spontaneous answers, show them answers that we have come up with on the page that is appropriate for that principle. Ask them to tell you which two or three of the behaviors that are listed would best communicate the principle to them. Take each principle that they chose through all the steps before you go on to discuss the next principle. If a parent has spontaneously come up with something on our list, put an "S" next to the behavior. They may or may not want to include these items as one of their three choices. If you have two parents present, not the mother's responses with M1, M2, M3 and the father's with F1, F2, F3.

Post Assessment Questionnaire for Nine Month Evaluation

Open-ended Questions

1. Since money is tight, hospitals, insurance companies and others that pay for services for children are always looking for places to cut. From a parent's perspective, do you think developmental follow-up services for premature babies are important services to offer? Why or why not?

2. For you as a parent, what do you think are the most important or most helpful parts of developmental testing? (Other ways of asking this question: If you could choose a few points about what I do to highlight as what is most important to you as a parent, what would they be? What do you like?)

3. Is there anything else you would like?

Note: For all following questions elicit this information:
--anything that I do especially helpful to you?
--how could someone communicate that?
--what would make you think that?
--etc.

Principles of Developmental Assessment/Intervention

Which of the following points would you consider most important for an assessor of your baby to have? Please number your first three choices.

1. To treat parents as partners and peers in the process of planning an evaluation and any necessary developmental follow-up for their child.

2. To share information openly and honestly with parents and give parents as much information as we can.

3. To respect and listen to parents' knowledge of their own child's behavior.

4. To convey that we care about both babies and their parents.

5. To check that our assessment results match the way a parent sees their child.

6. To arrange assessment sessions so we see a child's best performance, if possible.

7. To act as a resource for parents.

Subpoints--Things We Do To Implement the Principles

Principle #1: To treat parents as partners and peers in the process of planning an evaluation and any necessary developmental follow-up for their child.

Which of the following points communicate to you that we treat you as partners and peers in the process of planning an

evaluation and any necessary developmental follow-up for you child? Please number your first three choices.

--that we answer your questions and concerns.

--that we involve you in all suggestions and decisions.

--that we incorporate your comments about your child into discussions bout test results and into the written report.

--that we set up the assessment to meet both your infant's and your needs.

--that we inform you where the assessment reports go.

--other.

Principle #2: To share information openly and honestly with parents, giving parents as much information as we can.

Which of the following points communicate to you that we are sharing information about your child openly and honestly? Please number your first three choices.

--that we give you your child's developmental age levels and tell you what these age levels mean.

--that we explain what we're doing while we're doing the assessment.

--that we explain your child's strengths and weaknesses during the assessment, and explain what this means about your child's development.

--that we give you information about how you can help your child develop, including specific suggestions bout how to work with your child at home.

--that we tell you what the next steps will be in your child's development.

--that we tell you right after the assessment how your child did.

--that we explain and discuss the assessment results.

--that we explain where our conclusions and suggestions come from.

--that we explain the purpose of the assessment, areas covered by the test, what the test can and cannot accomplish.

--that we explain the principles of what we do in language that you understand.

--other

Principle #3: To respect and listen to parents' knowledge of

their own child's behavior.

Which of the following points communicate to you that we respect and listen to your knowledge of your child's behavior? Please number your first three choices.

--that we recognize that you are in charge of your baby and that we ar there to make suggestions to help your child develop.

--that we listen and note the information that you give us about your child.

--that we ask at the beginning of an assessment whether you have any specific concerns.

--that we ask you for information about your child that the test does not cover.

--that we ask for your suggestions or assistance when we are unable to elicit your child's response.

--that we allow your child to demonstrate his ability before questioning you as to your child's ability that he hasn't demonstrated.

--other

Principle #4: To convey that we care about both babies and their parents.

Which of the following behaviors convey to you as a parent that we care about you and your baby? Please number your first three choices.

--that we notice your child's strengths and weaknesses.

--that we listen to any concerns or questions that you have.

--that we have the time and flexibility to talk informally with you.

--that we explain in advance what you can expect to happen during the assessment. (We explain how much time the assessment will take, some of your child's behaviors that we will be looking at and that we do not expect your baby to pass all the items because we keep going until he can't do any more.)

--that we consult with you about convenience in scheduling, and whenever possible, accommodate both you and the baby's father.

--that we get reports to you within two weeks.

--that we regard each child as a unique individual with unique needs.

--other

Principle #5: That we check whether our assessment results match the way a parent sees their child.

What do we do that communicates to you that you and I see eye-to-eye about what your child is doing? Please list your first two choices.

--that we ask you for a comparison of what you see on the test and what you see at home.

--that your presences is considered important to the assessment process.

--that we explain the meaning of items during the assessment.

--other

Principle #6: To arrange assessment conditions so that we can see your child's best performance.

What do we do that communicates to you that we want to see your child's best performance? Please number your first three choices.

--that we take time to establish rapport with your child.

--that we pace the test according to your child's needs and give him all the time he needs.

--that we show sensitivity to the needs of your child.

--that we reschedule appointments when you feel your child is not well.

--that we plan the assessment with you to encourage your child's best performance in terms of time and place.

--that when we can't get your child to do something, we ask you for suggestions about how we can encourage him and sometimes we even ask you to elicit the activity.

--other

Principle #7: To act as a resource for parents.

Which of the following ways do we act as a resource for you? Please number your first three choices.

--that we help you obtain additional resources such as a physical therapist or an extra visit to the clinic when needed.

--that we have flexibility in the amount of time we spend with you.

--that we recommend developmental books for you to read.

--that we recommend age appropriate toys for your child.

--that we recommend games and exercises to enhance your child's development.

--other

Appendix J

RESEARCH PROCESS FOR BAYLEY ASSESSMENT/INTERVENTION SESSIONS

1. Pre-assessment interview on phone with parent:

--Use Pre-Assessment Interview Guide. Work through thoughts and questions, making notations on that form. Record answers to questions noted as "musts" on the form, including the Checklist of Assessment Options. Make other notations as applicable.

2. Plan for the assessment/intervention session:

--Using the pre-assessment interview information and your other knowledge of the family, go through the Planning Guide for Assessment Sessions or the Checklist for Assessment/Intervention. Asterisk the items of the assessment model that seem particularly important for this family. Record your reasons for asterisking these particular items.

3. Do the Bayley assessment/intervention:

--Use the Planning Guide for Assessment Sessions and/or the Checklist for Assessment/Intervention to guide the format of the sessions. Check off essential items of the model as you do them, using the Checklist for Assessment/Intervention during the assessment.

--After the assessment, go through the complete Planning Guide for Assessment Sessions and record notes about the assessment/intervention process with this family.

4. Write a report of the assessment, using the Assessment Report Format as a guide.

5. Go back to the family for the post-assessment interview, using the guide for that session to organize the interview. Afterward, write a summary (about one page) of the parents' comments during the interview, in the form of expanded lists they gave in response to the three questions that guide that interview. (These are the lists you jotted down and used for member checking during the interview itself, somewhat expanded.)

6. Listen to the tape of the post-assessment interview. Add to your notes abut the interview as appropriate.

Optional: experiment with combining the assessment/intervention and post-assessment interviews, and record thoughts about how the different format works (advantages and disadvantages of doing these two sessions in one or two visits). If using this option, mail the Bayley report to the family, and follow up with a phone call to discuss the report and answer their questions.

Appendix K

FINAL INTERVIEW QUESTIONS

Note: Add an individualized portion for each family: do final interview member checking.

A. Define in your own terms what this study has been about. What do you think is useful about studying what parents want during follow-up for their children?

B. As the parent of a premature child, you probably worried about whether your child would be all right. Our research is about how parents want professionals to treat them and their babies during the first year of follow-up with their infants. What was helpful to you during this period? What was unhelpful to you during this period?

1. How can we help you during this follow-up period? Is there anything that anyone said to you or did for you that was particularly useful? Was there anything that you read? What helped you met the challenges of having a premature baby? How do you feel about these challenges now?

2. Is there anything that anyone said to you or did for you during this period that was particularly helpful?

3. How can we help you help your child develop? Is there anything that anyone did or showed you or that you discovered yourself that was particularly helpful? Is there anything that you learned in this process that you think is important for other parents to know?

4. Looking back over the past year, what would you say were the biggest challenges, hurdles, or problems that you faced as the parent of a premature baby? How do you feel about these issues now? (If they have overcome these hurdles, what helped them most, either inside themselves or outside in their environment, to overcome these issues? If they still have these issues, have they lessened? If so, what helped them do this?)

C. How do you think professionals and parents should interact during developmental follow-up? Do you think parents should mostly listen to professionals, or do you think professionals should mostly listen to parents? What would the ideal or perfect relationship between parents and professionals be?

1. Do you interact with professionals in the way that you want to most of the time? Do you sometimes not ask questions or tell them what is important to you? Is it easier for you to talk to professionals in some moods or on some days than other? Which days, which moods? Is it easier for you to talk to some professionals than others? If so, what are the differences in the people, or what makes the difference?

2. Would you see the ideal professional/parent relationship as a partnership between parents and professionals? with professionals as consultant? with professionals as authorities? How would you describe this relationship? Do you feel that your relationship with your

developmental specialist has been a ___? If yes, why? If no, why? (Do you feel that your relationship with your neonatalogist was a ___? With your physical therapist? With your nurse?)

D. The title of our research project was "Assessment as Intervention." Our theory was that the experience of our coming out to your home and assessing and talking with you about your child would affect both your and your child. In what ways, if any, have your interactions with your developmental specialist affected the way you looked at or interacted with your child? In what ways, if any, has it affected you? (Has our coming had nay meaning or purpose for you?)

E. If a friend who had recently given birth to a premature infant asked you what to look for in a developmental follow-up program, what advice would you give?